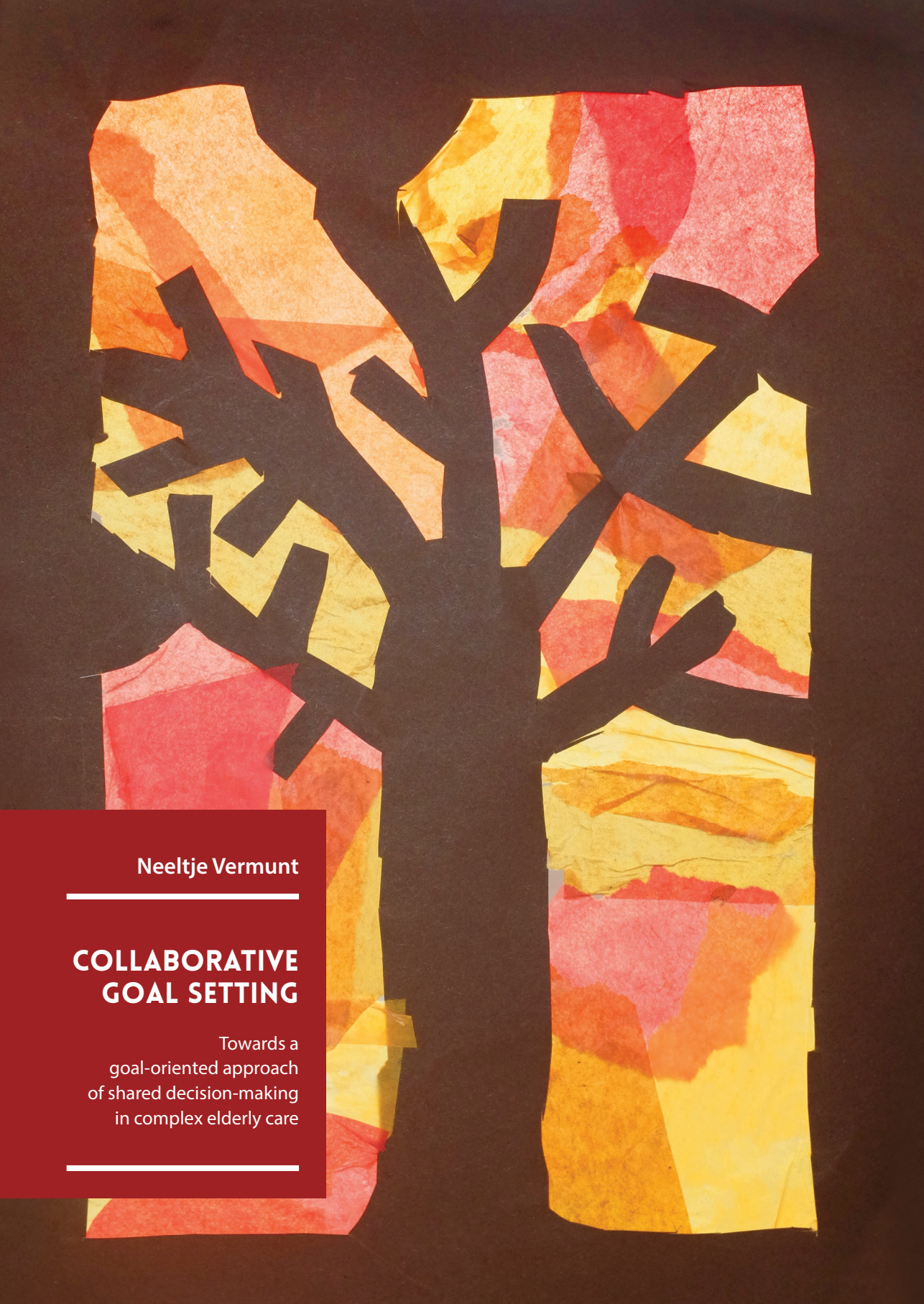

Neeltje Vermunt

COLLABORATIVE GOAL SETTING

Towards a goal-oriented approach of shared decision-making in complex elderly care

Collaborative goal setting

Towards a goal-oriented approach of shared decision-making in complex elderly care

Colofon

For reasons of consistency within the thesis, language (British-English) and some terms have been standardised throughout the text. As a consequence the text may slightly differ in these respects from the articles that have been published.

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Collaborative goal setting

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Content

List of abbreviations

ACP	Advance Care Planning
AGP	Assessment of Goals and Priorities
CBA	Controlled Before-After (studies)
CCDD	Complex Chronic Disease and Disability
CCM	Collaborative Care Model
CDSM	Chronic Disease Self-Management
CG	Clinical Geriatrician
CGS	Collaborative Goal Setting
CHD	Chronic Heart Disease
CI	Confidence Interval
CoC	Continuity of Care
COINCIDE	COllaborative INterventions for CIrculation and DEpression
COREQ	Consolidated Criteria for Reporting Qualitative Research
CPG	Clinical Practice Guideline
CWF	Commonwealth Fund
DM	Diabetes Mellitus
EBM	Evidence Based Medicine
ECA	Effective Collaborative Action
EHR	Electronic Health Record
EPOC	Effective Practice and Organization of Care
ePRO	Electronic Patient Reported Outcome
ES	Effect Size
GC	Guided Care
GCN	Guided Care Nurse
GCPFF	Guided Care Program for Family and Friends
GP	General Practitioner
GS	Goal Setting
G-SDM	Goal-oriented Shared Decision-Making
HOPES	Helping Older People Experience Success
HCC	Hierarchical Condition Category
ICF	International Classification of Functioning Disability and Health
ICT	Information and Communication Technology
IQR	InterQuartile Range
ISCOPE	Integrated Systematic Care for Older PEople
ITS	Interrupted Time Series
M	Mean

MOOSE	Meta-analysis Of Observational Studies in Epidemiology
N	Number
N/A	Not Applicable
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NP	Nurse Practitioner
NRCT	Non-Randomised Controlled Trials
NSAID	Non-Steroidal Anti-Inflammatory Drugs
OR	Odds Ratio
PA	Physician Assistant
PACIC	Patient Assessment of Chronic Illness Care
PCC	Patient-Centred Care and Person-Centred Care
PCP	Primary Care Physician (or Practice)
PrefCheck	Preferences in treatment planning for older patients
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT	Randomised Controlled Trial
RQ	Research Question
SD	Standard Deviation
SDM	Shared Decision-Making
SE	Standard Error
SMI	Serious Mental Illness
STROBE	Strengthening The Reporting of OBservational studies in Epidemiology
UK	United Kingdom
USA	United States of America

CHAPTER 1

General Introduction and Outline

Background

Person-centred care (PCC)[1] is defined as health care that is 'respectful and responsive to individual patient preferences, needs, and values and ensures that patient values guide all clinical decisions' [1]. Shared decision-making (SDM), defined as 'an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences' [2], fits into this perspective of person-centred care [3]. SDM actually can be seen as fundamental to person-centred care [4 5].

Caring for patients with multimorbidity is most common in daily clinical practice. Providing person-centred care for patients with multimorbidity requires a transition from disease-specific to person-centred models of care delivery [6]. Person-centred care approaches can be seen as essential to address the highly variable needs of this patient population [1 7-9]. In daily practice person-centred care for patients with multimorbidity can be supported by adopting goal-oriented approaches in decision-making [10 11]. In this thesis we describe the results of the 'Collaborative Goal Setting' study, which was designed to investigate goals and goal setting (GS) in relation to SDM in the context of patient goal-oriented health care in elderly with multimorbidity.

Shared decision-making

Shared decision-making is defined as 'an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options and to achieve informed preferences [2]. SDM means that clinicians and patients make decisions together in a partnership, using the best available evidence by considering available options and the likely benefits and harms of each, communicating their preferences and selecting the course of action best fitting these preferences. A SDM approach respects patients' autonomy and stimulates patients' engagement [2]. Main goal of SDM is to make decisions in a manner consistent with a patient's wishes [12]. SDM can be used when two comparable, but distinctly different treatment options exist [13]. In specific cases decision aids can be used. These are tools that describe options available and help patients to understand these options as well as the possible benefits and harms [14]. Wiser choices tools (structured graphical displays of risks) and option grids (one-page summaries of frequently asked questions considering treatment choices) are tools developed for clinical encounters specifically [14]. SDM can be described as a 'SDM Continuum' to emphasise that SDM necessarily will take different forms in different situations

[1] Considering terminology both *patient*-centred and *person*-centred care are used in the literature. We prefer the term *person*-centred care. We did not replace *patient*-centred care in referrals to other literature.

considering roles and input in the process, ranging from patient- or agent-driven, through equal partners till physician-driven [12]. In the whole continuum patients' values should be taken into account. Family members or other health care professionals involved can also be included in the decision-making team.
SDM is shown to improve patients' knowledge about their condition and treatment options, to increase patient satisfaction with care, and improve patient self-confidence and self-care skills [15]. It improves quality of life and the relation between clinician and patient [16 17]. Although implementation of SDM has shown positive effects, the SDM model was mainly developed in cure situations in hospital settings, and it may be deficient in more complex care situations [18].

Possible causes of deficiencies in SDM in complex care situations
Despite evidence of added value and efforts for further implementation, SDM is not routine yet [3 14 18-22]. In complex care situations, this may be due to deficiencies in the current SDM approach. In this context we consider the following factors important:
- Main focus of current medical practice
- Multimorbidity
- Difficulties in incorporating preferences and values

Main focus of current medical practice
Medicine has developed from a single disease-outcome-based paradigm. Medical science had a primary focus on the nosology and pathophysiology of single diseases and devoted little to no study to the coexistence of multiple chronic conditions in a single patient. This led medical practice to focus on deviations from biological norms instead of patients' needs and a culture which values managing each disease as well as possible according to guidelines and population goals [10 23-28]. In addition, culture remains predominantly clinician-centric (doctor knows best) instead of a clinician-patient partnership [28] and clinicians are trained to address disease prevention and risk reduction, generally with a focus on the highest clinical risk problems [29].
More and more, it has become clear that the single disease-outcome-based paradigm no longer fits the medical necessities and needs of most patients, and that a more holistic, patient-centred view should be developed [10 24-27].

Multimorbidity
Decision-making with older patients with multimorbidity, i.e. the co-occurrence of multiple chronic conditions, is challenging. This is due to several factors. Patients often present at a clinical encounter with a large number of medical issues (and accompanying medications). Some of the underlying conditions may be clinically dominant or highly symptomatic thereby demanding a substantial amount of a clinician's time and drawing attention away

from other health problems. Furthermore, different conditions may require separate, time-intensive treatment plans [30]. In addition, clinicians often face the challenge of a shortage of clinical trial evidence describing interactions among conditions and treatments in patients with multimorbidity [30]. Disease priorities can be interfering [31 32] and the need of adherence to multiple disease guidelines can be problematic [28]. Disease-specific guidelines are often not applicable to older patients with multiple conditions [32-35] and compliance to multiple single disease guidelines can lead to polypharmacy, high treatment burden, inattention to social and personal context, and failure to align care with personal goals and preferences [36 37]. When having multiple chronic conditions, most of the times, several clinicians are involved and concentrate on managing different conditions and monitoring different disease-specific outcomes. Patients are at risk of receiving care that is fragmented and not always focusing on what matters most to them [33].

Difficulties in incorporating values and preferences in clinical decision-making

For older adults with multiple chronic morbidities facing conditions with clinical uncertainty (e.g. cancer) aligning health outcomes with the individuals' values and goals is complex and challenging [38-40]. Clinicians may struggle to help people prioritise their values, define treatment goals and frame preferences in ways that are clinically relevant and personally meaningful (aligned with one's values) when faced with multiple diagnostic and treatment options [41 42]. Patients and clinicians may also have different perspectives and priorities in this respect [32 35 39 42-45]. Clinicians tend to make inaccurate assumptions about patient values and preferences [10] and part of clinicians happen to think that they know what is best for patients [28]. Decision-making with patients with a chronic condition is complicated further by changes in health, priorities and experiences in prior treatments [32 46].

Goal-oriented decision-making

To address the challenges of decision-making with older patients with multimorbidity health care delivery must be transformed to provide personalised care to people with multimorbidity, meaning a transition from disease-specific to patient-centred models of care delivery [6]. For a patient-centred approach, it is necessary to explore patients' goals, preferences and needs and to center care and decision-making around these [46 47]. Health priorities should be incorporated into care decisions and the relationship across patient and clinician realigned [28]. Tinetti et al. recommended a shift from a disease orientation to a patient goal-orientation [11]. In goal-oriented health care [2], care is personalised to adjust it to a patient's goals,

[2] For a patient goal-oriented approach in health care several terms are used in the literature, namely patient priority-directed decision-making and care, patient goals-directed care, patient goal-oriented health care and goal-oriented patient care. We chose patient goal-oriented health care to reflect the relevance of goals and goal setting and the shared/collaborative character of this approach.

preferences and needs [10 48]. This goal-oriented approach relates to making health care decisions, assessing outcomes, and measuring success [10]. Within this approach a patient's health outcome priorities and goals are ascertained and the diseases and other modifiable factors, impeding these goals are identified. It focuses decision-making on individually desired rather than universally applied health states. A patient goal-oriented approach enables to focus on outcomes that span conditions, to align treatments towards common goals and to make individual prioritisation in trade-offs possible [10]. After exploring the likely effect of alternative treatments, patient and clinician engage in a process of SDM informed by this information [11]. Goals and priorities and SDM are key elements for this approach of patient involvement in decision-making.

For individual patients, a goal-oriented approach in health care could probably increase patient involvement and contribute to a patient's wellbeing and quality of life. In a separate development, Bodenheimer and Handley defined collaborative goal setting (CGS) as 'a process by which health care professionals and patients agree on a health-related goal' [38], acknowledging health-related goals and GS in the context of behaviour change and action planning for chronic conditions in primary care settings, but not necessarily relating them to SDM. Among patients with diabetes aged 18+ years, patient reported use of more GS was associated with greater perceived self-management competency and increased level of trust in the physician, which in turn were associated with improved glycaemic control [49]. An explicit discussion of goals of care may promote effective communication and may more effectively engage people in treatment planning [42 50]. For societies this approach and change in focus could probably also contribute to the long-term quality, accessibility and affordability of the health care system [10 11 33 46 51-53]. Especially in the present context of ageing populations, and the increasing interest of health care contributing to a patient's wellbeing and quality of life, a patient goal-oriented approach in health care could be beneficial for individual patients and societies.

Three major challenges to establish a goal-oriented approach in decision-making

We identified three major challenges preventing a switch from a disease-oriented to a goal-oriented approach in decision-making:

1. Sharing goals is not common practice yet.
2. Lack of insight in types of goals and goal setting approaches.
3. Unclear conceptual relation between goal setting and SDM.

Sharing goals is not common practice yet.

From the 2014 CWF Survey followed that for adults aged 65 or older, having a chronic condition, rates of respondents sharing goals with a professional vary from 23% (Sweden), till 59% (UK), with 9 of 11 countries having rates of less than 50% [54]. CGS has not been a traditional part of health care encounters [41 55].

Lack of insight in types of goals and goal setting approaches.

Health-related goals arise not only from health but also from other dimensions like social context or wellbeing [10 35 48 56]. These different types of goals, which are often implicit, can be in conflict [57]. When treatments involve trade-offs, the best option depends on a patient's preferences [58]. Older patients with multiple chronic conditions, vary in their health outcome goals and in what they are willing and able to invest to achieve those outcomes, when facing trade-offs which require difficult choices [28 33]. The challenge for older persons with multiple conditions is that these trade-offs encompass both many different specific diseases and non-disease-specific health domains.

Types of goals, their interrelatedness and the way they relate to concepts as preferences, priorities, and values are unclear. The concepts of values, goals, and preferences are often used interchangeably, although they are not the same thing; values relate to a set of fundamental beliefs about one's self and life being stable over time despite changing circumstances and context [41 59-61]. Health-related values direct health behaviours and decisions by providing emotion and motivation [41]. According to Bradley et al. [50] and Naik et al. [41], goals and preferences, in contrast, can be seen as more context or circumstance specific.

In addition, there is a lack of insight in approaches to actually clarify values and elicit patient preferences in a structured and consistent manner [62]. Approaches for reconciling clinicians' own and their patients' priorities and setting goals are also not clear [35]. GS practices have not been explored extensively in the context with older patients with multimorbidity [57]. The National Institute for Health and Care Excellence (NICE) emphasised the relevance of discussing and exploring a patient's values, priorities and goals and recording these in a individualised management plan, but there is no advice on methods to have this discussion [63 64]. Naik et al. [41] examined health-related values probably guiding how older multimorbid adults who recently faced life-threatening cancer, frame their goals for care and treatment preferences. Eliciting individuals' sense of their values during clinical encounters may more effectively align treatments with goals of care [41]. Kuluski et al., found little goal alignment across triads of complex patients, caregivers and clinicians, identifying the need for research on how to embed GS and alignment as a standard of practice [65]. Little is known about the process clinicians use to set goals in the presence of complexity and we lack evidence to support best practices in GS for complex patients [66]. It is clear, that CGS in the context of older patients with multimorbidity is just evolving.

Unclear relation between goal setting and SDM.
SDM needs clarifying values and eliciting patient preferences [46 62]. A common approach to SDM is to elicit individuals' preferences for treatments, tests, or procedures [60 67]. Preference, rather than goal elicitation helps people make decisions that typically involve a discrete set of effective treatment options that relate to a single medical condition [60 61], but this form of preference elicitation is less helpful for individuals with multiple morbidities, who often have to make numerous and conflicting decisions and choices [41]. A goal-oriented approach could be useful, but research is only starting to incorporate explicit goals and GS in models of SDM [18].

Study rationale and research objectives
Although a patient goal-oriented approach is advocated more and more, sharing goals is no common practice. Starting from a patient goal-orientation in decision-making, details on goal types, and the concepts of GS and SDM and practical approaches for daily practice within this approach are lacking. This study was designed to contribute to the knowledge on CGS in relation to SDM in the context of patient goal-oriented health care. With our results we try to contribute to an evolvement of health care for older patients with multimorbidity from a disease-specific to a patient goal-orientation by combining research focusing on theory development and practice-oriented research.

For this thesis we formulated the following research objectives in the context of patient goal-oriented care for older patients with a chronic health condition or multimorbidity:
1. To analyse the concept of goal setting in the context of shared decision-making.
2. To improve the knowledge base for the concept of goal-orientation and types of goals in decision-making.
3. To evaluate the availability and effects of interventions on collaborative goal setting.
4. To identify possible factors having impact on sharing goals in daily practice.

Our research focused on the following research questions, which are visualised in Figures 1.1 and 1.2:
1. What are clinicians' views on the concept of goal setting in the context of SDM?
2. What are clinicians' views on goal-orientation in the context of CGS and SDM?
3. What are effective interventions supporting collaborative goal setting or health priority setting?
4. Which characteristics of patients, patient-professional engagement, communication and context factors have impact on the probability that health care professionals will discuss goals with older patients with chronic diseases?

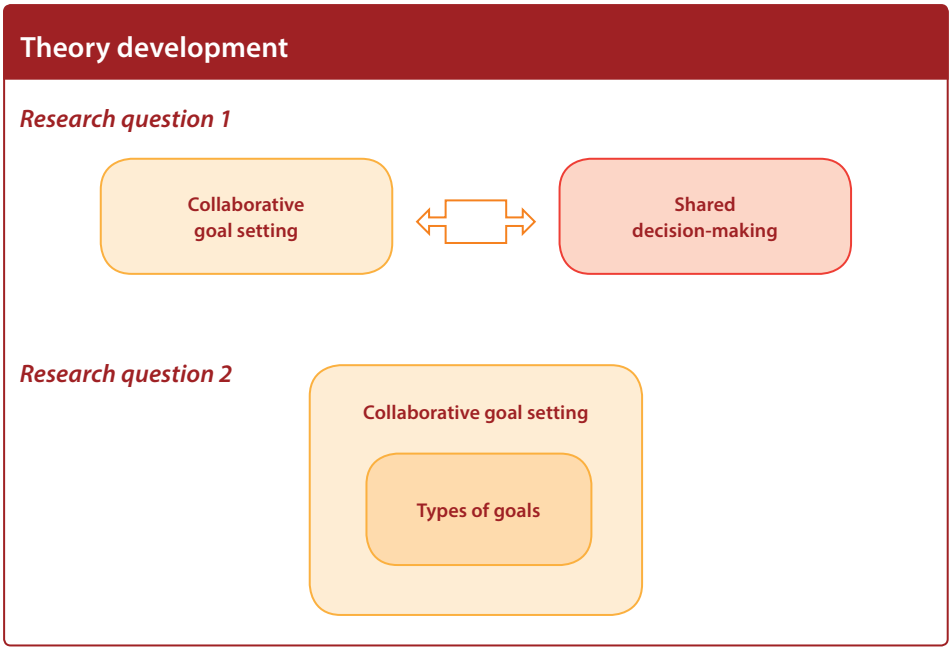

Figure 1.1 **Thesis outline research questions 1 and 2**

Note: This figure provides an outline of the first two research questions, which focus on further theory development.

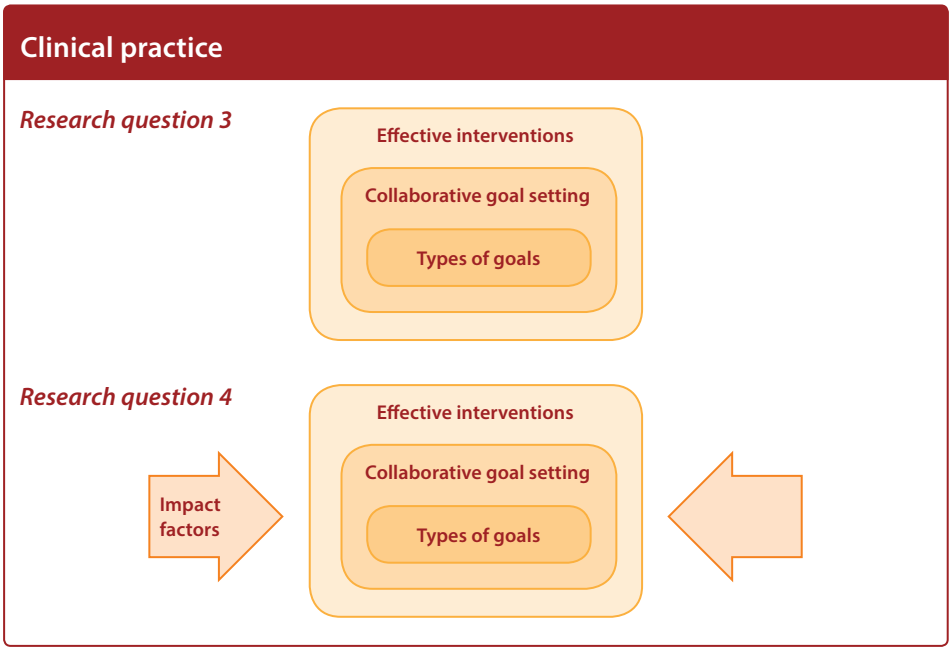

Figure 1.2 **Thesis outline research questions 3 and 4**

Note: This figure provides an outline of the third and the fourth research questions, which focus on clinical practice.

Design and thesis outline

The first research objective to analyse the concept of goal setting in the context of shared decision-making is addressed in *chapter 2*. *Chapter 3* deals with the **second research objective** to provide knowledge on types of goals in decision-making. The **third research objective** to identify and evaluate studies on the effects of interventions supporting CGS or health priority setting compared to usual care is addressed in a systematic review of the literature in *chapter 4*. *Chapter 5* addresses the **fourth research objective** to identify possible factors having impact on sharing goals in daily practice by analysis of the Commonwealth Fund Survey 2014, which specifically targeted the population of community-dwelling adults, aged fifty-five and older. For objective 1 and 2, we used two qualitative analysis methods analysing interview data of Dutch general practitioners and clinical geriatricians, both involved in decision-making and care for older patients with multimorbidity, but in different settings. Finally, *chapter 6* summarises and discusses the main findings, reports on methodological strengths and limitations and discusses implications and recommendations for clinical practice, further research and health policy.

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CHAPTER 2

Goal setting is insufficiently recognised as essential part of shared decision-making in complex care for older patients: a framework analysis

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Abstract

Background: Multimorbidity challenges decision-making processes and asks for paying attention to patients' goals, preferences and needs. However, goal setting is not yet widely recognised as a core aspect of the approach that has been called shared decision-making. This study aims to analyse clinicians' perceptions of the concept of goal setting within the context of shared decision-making with older patients with multimorbidity.

Methods: Semi-structured interviews with general practitioners and clinical geriatricians were analysed by framework analysis. The integrative model of shared decision-making with the additional component of goal setting was used as categorisation matrix.

Results: Sixteen of 33 clinicians explicitly mentioned 'Goal setting' as an integrated component, when giving their definition of shared decision-making. In addition, many clinicians confirmed 'Patient values and preferences' (n=16), 'Doctor knowledge and recommendations' (n=19) and 'Make or explicitly defer a decision' (n=19) as relevant elements of shared decision-making. Seventeen clinicians (6 GCs and 11 GPs) did not mention 'Goal setting' as an explicit component. Our analysis revealed two potential reasons for this observation. Next to the use of other terminology, part of clinicians viewed CGS and SDM as separate but related processes.

Conclusions: The results of these interviews support recent theoretical insights that models of shared decision-making that do not contain an explicit goal setting component are deficient, and have overlooked an important aspect of engaging patients in decision-making, particularly where patients have complex multiple long-term conditions. We conclude that a comprehensive SDM approach of shared decision-making with older patients with multimorbidity could be developed further by including explicit and unequivocal goal setting to sufficiently meet the expectations and needs of clinicians practising decision-making with these patients.

Background

Goal setting has emerged as a critical part of taking care of patients with two or more long term conditions, and yet paying attention to patients' goals is missing in the approach that has been called shared decision-making. Is this an oversight or was it deliberate? Where there is multimorbidity, defined as the coexistence of two or more chronic diseases or conditions, clinical priorities can compete with one another, and patients have different perspectives and priorities to clinicians [1-10].

To address these challenges, many have advocated paying attention to patients' goals, preferences and needs [11-14]. For instance, Tinetti et al. recommended a shift from a disease orientation to a patient goal-orientation [7]. In this approach, patients' priorities and goals are ascertained and the problems impeding these goals are identified. In the context of ageing populations, a goal-oriented approach to health care could be beneficial at many levels [7 8 15-17].

Shared decision-making (SDM) would seem to be an approach that would be highly compatible with taking a goal-orientation to care. Yet, the role of goals and goal setting were not explicitly described in this and other SDM models as such [18-21]. Based on an analysis of five prominently cited SDM models, Makoul and Clayman in 2006 [18] identified the most frequently invoked elements and qualities and presented an integrative model for SDM. This integrative model of SDM is restricted to the essential elements, as presented in Box 2.1. Makoul's integrative model is intended to encompass different clinical contexts, types of decisions and levels of involvement.

In a separate development, Bodenheimer and Handley coined the term collaborative goal setting (CGS) as 'a process by which health care professionals and patients agree on a health-related goal' [22], acknowledging health-related goals and goal setting in the context of behaviour change and action planning for chronic conditions in primary care settings, but not necessarily relating them to SDM. CGS has been evaluated in varying rehabilitation settings [23-26]. Considering daily practice of CGS with older patients with a chronic disease or multimorbidity, based on the 2014 Commonwealth Fund Survey of adults aged 65 or older, having at least one chronic condition, rates of sharing of goals with a health care professional, according to the respondents, varied from 23% (Sweden) till 59 % (UK), with 9 of 11 countries having rates below 50% [27]. Furthermore, there is a relative lack of insight in the process clinicians use to set goals in the presence of complexity and little evidence to support best practices in goal setting for complex patients [28]. In a recent systematic review, we concluded that CGS is often a component of complex multifactorial interventions [29]. It is clear, that CGS in daily practice of caring for older patients with multimorbidity is just evolving.

Recently, the absence of goal setting in shared decision-making models has been noticed, and changes are being introduced to try and address the deficit. In 2012, Elwyn et al. developed a SDM model consisting of a Choice Talk, Option Talk and Decision Talk, which

was updated to Team Talk, Option Talk and Decision Talk [21 30]. Van der Pol et al. [31] proposed a SDM model especially suitable for older patients with multimorbidity based on this three-step-model by adding a fourth term, namely Goal Talk. However, the conceptual link between CGS and SDM is not self-evident, since Rose et al. [32], conducted a systematic review on SDM *within* CGS in rehabilitation settings.

It is clear that a coherent description of how best to accomplish SDM when older patients have complex multimorbidity has not yet been fully established. Although absent from early models of SDM, it is clear that goal setting and goal attainment are vital parts of how to accomplish the best plans for patients who need to juggle the burden of illness against the burden of treatments. However, it is as yet unclear how goal setting fits into the concept of SDM. It would be helpful to achieve more clarity about how concepts of SDM and goal setting might fit together in the context of older patients with chronic multimorbidity not only for theory development but also to support further development of practical approaches. General practitioners (GPs) and clinical geriatricians (CGs), both involved in care for older patients, might be able to use their experience of daily care and decision-making with older patients with multimorbidity to contribute to a better understanding of the relationship between SDM and goal setting.

Our aim was to examine whether clinicians view goal setting as a component of SDM, and if so, whether care for patients might be facilitated by integrating explicit goal setting into an SDM approach. For this purpose, we conducted and analysed interviews with GPs and CGs using a framework approach [33 34].

Methods

We conducted a qualitative study based on semi-structured interviews of expert CGs and GPs. A framework approach was used for analysis [33 34]. The integrative model of shared decision-making of Makoul et al. [18] with the additional component of goal setting was used as categorisation matrix. The Consolidated Criteria for Reporting Qualitative Research (COREQ) [35] and the Guidelines for authors and reviewers of qualitative studies [36] were used for design, performance and reporting. Additional file 2.1 reports on these COREQ criteria in relation to our research.

Sampling

Potential participants were selected using a purposive and snowball method, to recruit professional experts in geriatric care in a hospital and community setting [37]. We invited GPs specialised and experienced in geriatric care, as well as experienced CGs working in an academic or non-academic teaching hospital, performing research, teaching, developing

or implementing specific innovations in care for older patients. In the sampling we tried to ensure that the numbers of GPs and CGs included would be comparable. To obtain further diversity of perspectives we tried to ensure that different types of practice and practice location (rural or not) would be represented in the GP sample and different types of hospitals for the CGs. For both CGs and GPs we tried to ensure that all Dutch regions were represented. Sampling potential participants was initiated by interviewing a GP and a CG, both of whom were familiar to the interviewer. We also recruited GPs at a meeting of general practitioners specialised in geriatric care. Potential participants were approached by email.

Data collection

We drafted an interview guide based on two viewpoints about goal-oriented health care for older patients with chronic multimorbidity [7 14]. SDM, CGS and effective collaborative action were the main topics. We defined *effective collaborative action* as clinicians and patient deciding on and performing diagnostic and treatment steps in line with collaborative goals, which were set between patient and clinicians or with other involved caretakers. Definitions were not given to the interviewees. Main topics and subtopics are presented in Additional file 2.2.

In the introduction of the interviews, the clinicians were asked to use the context of regular care for community dwelling older patients (age >75 years) with a chronic disease or multimorbidity without further specifications. Specific questions could differ for better understanding of certain (sub)topics. All interviews were conducted by the same interviewer (NV) and lasted approximately 60 minutes. Two pilot interviews were conducted with a clinical geriatrician and a general practitioner. Main topics and subtopics were not changed based on the pilot interview nor during the conducting of the interviews. Five interviews were face-to-face, the others were held by telephone, as the clinicians' busy schedules and varying locations required flexibility. The face-to-face interviews were held at the interviewee's office. Interviews were audio-recorded and transcribed. Field notes were kept and analytical memos drafted during data collection and analysis. Sample size was guided by theoretical saturation [38]. After the identification of no newly emerging data, we conducted two further interviews as confirmation.

Analysis

A framework approach was used for data analysis in two phases [33 34]. In the first phase, we used open coding. All topics of the first five interviews were coded independently by two data coders (NV, MH). Initial codes were compared, discussed, grouped and categorised in order to determine a working analytical framework taking into account reflexivity. Remaining interviews were coded by one researcher (MH) and checked by the other (NV).

In weekly meetings, the researchers (NV and MH) compared, discussed and agreed on the coding of the transcripts, including the creation of additional codes and further refinement of analysis. For the purpose of this study, in the second phase of analysis, we further analysed the themes 'SDM concept' and theme 'Links between the concepts of SDM and CGS'. For this purpose, we used a SDM categorisation matrix based on the essential, ideal and general elements of Makoul et al.'s integrative model of SDM, shown in Box 2.1 [18]. We added a new category to this SDM categorisation matrix: goals/goal setting. We charted the data in this categorisation matrix and findings were interpreted.

Atlas-ti 7.1.15 software was used in data coding and analysis. We used the consolidated criteria for reporting qualitative research (COREQ) [35], see Additional file 2.1. Findings were discussed in regular meetings between NV and MF and adjusted further after review by the research team. Illustrative quotations were selected to highlight our findings and were translated from Dutch to English by a professional translator.

Results

Interview and participant characteristics

Response rates of CGs and GPs were 86% and 54%, respectively, resulting in a final sample of 33 clinicians, 18 CGs and 15 GPs. The first author (NV), a former GP, conducted the interviews between November 2012 and April 2013. Some interviews were conducted face-to-face and others by telephone. All interviews lasted approximately 60 minutes. The mean age for GPs was 51 (n=15) and 48 for CGs (n=18); 60% of GPs and 50% of CGs were female. On average, GPs had 16 years of professional experience and CGs had 10 years. Additional participant characteristics are presented in Table 2.1.

Table 2.1 **Basic characteristics of participants**

Characteristics	General practitioner (n = 15)	Clinical geriatrician (n = 18)
Age, *mean (SD)* (years)	51 (6.6)	48 (8.6)
Gender, *n* (% men)	6 (40)	9 (50)
Practice type, *n* (%)		N/A
Single	1 (7)	
Duo	2 (13)	
Group/health centre	12 (80)	
Practice location, *n* (%)		N/A
Rural area	3 (20)	
Urbanised rural area	5 (33)	
Urban area	7 (47)	

Characteristics	General practitioner (n = 15)	Clinical geriatrician (n = 18)
Physician assistant in geriatric care*, *n* (% yes)	12 (80)	N/A
Type of hospital, *n* (%)	N/A	
Academic centre		3 (17)
Community hospital		9 (50)
Mental care facility		2 (11)
Non-academic teaching hospital		4 (22)
Researcher, *n* (% yes)	5 (33)	9 (50)
Supervisor, *n* (% yes)	3 (20)	11 (61)
GP specialised in geriatric care, *n* (% yes)	9 (60)	N/A
Years of professional experience, *median* (range)	16 (3 - 34)	10 (3 - 22)

Note: N/A = not applicable; SD = standard deviation; GP = general practitioner;
*in GP practice

Main elements of SDM according to CGs and GPs

Makoul and Clayman in 2006 [18] identified the most frequently invoked elements and qualities and presented an integrative model for SDM, which is presented in Box 2.1.

Box 2.1 **Essential elements, Ideal elements and General qualities of SDM by Makoul and Clayman** [18]

Essential elements	Ideal elements	General qualities
Define/explain problem	Unbiased information	Deliberation/negotiation
Present options	Define roles (desire for involvement)	Flexibility/individualised approach
Discuss pros/cons (benefits/risk/costs)	Present evidence	Information exchange
Patient values/preferences	Mutual agreement	Involves at least two people
Discuss patient ability/self-efficacy		Middle ground
Doctor knowledge/recommendations		Mutual respect
Check/clarify understanding		Partnership
Make or explicitly defer decision		Patient education
Arrange follow-up		Patient participation
		Process/stages

Note: The integrative model of SDM is restricted to the essential elements because of its intention to encompass different clinical contexts, types of decisions and levels of involvement. Ideal elements may enhance the SDM process but are more applicable to some encounters than others and not necessary for SDM to take place. General qualities provide an overall sense of SDM, however these are not specific to SDM.

As already has been argued, Makoul's integrative model is intended to encompass different clinical contexts, types of decisions and levels of involvement. To investigate whether clinicians view goal setting as an essential component of SDM, we added the component of 'Goal setting' to the integrative model to constitute a categorisation matrix.

Table 2.2 **Categorisation matrix for SDM with older patients with multimorbidity**

	GP_01	CG_02	CG_03	GP_04	CG_05	GP_06	CG_07	CG_08	GP_09	GP_10	CG_11	CG_12	GP_13	CG_14	GP_15	CG_16	CG_17	CG_18	CG_19	GP_20	GP_21	CG_22	GP_23	GP_24	CG_25	GP_26	GP_27	GP_28	CG_29	CG_30	GP_31	CG_32	CG_33
Essential elements																																	
Define/explain problem				x	x							x							x				x			x		x		x		x	x
Present options			x			x		x	x		x	x		x			x											x		x		x	
Discuss pros/cons*					x		x	x	x		x						x									x		x					
Patient values/preferences	x		x	x	x		x	x	x	x			x	x		x					x	x				x		x	x	x			
Discuss patient ability/self-efficacy				x																													
Doctor knowledge†	x		x	x	x	x	x	x		x		x	x	x		x						x				x		x	x	x		x	x
Check/clarify understanding									x	x			x																				
Make or explicitly defer decision						x			x	x	x	x	x		x		x	x	x		x	x	x	x	x	x		x		x		x	
Arrange follow-up					x																				x								
Ideal elements																																	
Unbiased information			x		x																	x											
Define roles ‡																																	
Present evidence										x																							
Mutual agreement						x			x	x					x		x		x	x	x						x						
General qualities																																	
Deliberation/negotiation				x			x					x	x	x	x					x			x			x		x	x				
Flexibility §				x	x						x	x						x															
Information exchange							x							x																				
Involves at least two people																																	
Middle ground																																	
Mutual respect													x																				

	GP_01	CG_02	CG_03	GP_04	CG_05	GP_06	CG_07	CG_08	GP_09	GP_10	CG_11	CG_12	GP_13	CG_14	GP_15	CG_16	CG_17	CG_18	CG_19	GP_20	GP_21	CG_22	GP_23	GP_24	CG_25	GP_26	GP_27	GP_28	CG_29	CG_30	GP_31	CG_32	CG_33
Partnership		x		x														x	x	x			x		x				x			x	x
Patient education																																	
Patient participation		x							x	x	x		x			x	x				x	x		x				x				
Process/stages	x																																
Goals and/or goal setting		x	x	x	x		x				x	x				x		x	x	x					x		x		x		x	x	

*benefits/risks/costs

† and recommendations

‡ desire for involvement

§ individualised approach/cyclical

Note: This table shows the categorisation matrix and results per clinician. The integrative model of shared decision-making of Makoul and Clayman[18] completed with the additional element goals and/or goal setting was used as categorisation matrix. At the horizontal axis the interviewees are provided, with GP referring to a general practitioner and CG to clinical geriatrician. The vertical axis shows the essential elements, ideal elements, general qualities and the additional element goals and/or goal setting. Essential elements are elements being conditional for the process of SDM. Ideal elements may enhance the experience of SDM, but relevance, necessity and applicability are dependent on the type of encounter. General qualities are useful in providing an overall sense of SDM, but are not reducible to specific behaviour.

Essential elements of the integrative model of SDM mentioned by half or more than half the clinicians were: 'Patient values/preferences' (n=16), 'Doctor knowledge/recommendations' (n=19) and 'Make or explicitly defer decision' (n=19). Essential elements of the integrative model mentioned by less than half the clinicians were: 'Define/explain problem' (n=10), 'Present options' (n=11), 'Discuss pros and cons' (n=8), 'Patient ability/self-efficacy' (n=1), 'Check/clarify understanding' (n=3) and 'Arrange follow-up' (n=2). Sixteen of clinicians interviewed mentioned 'Goal setting' as an essential component.
Table 2.2 provides the results per clinician related to mentioning elements of the integrative model and the additional component of goals or goal setting. Although lacking in the original integrative model and in addition to 'Patient values/preferences', 'Doctor knowledge/recommendations' and 'Make or explicitly defer decision', 'Goal setting' was explicitly mentioned by almost half of clinicians interviewed and can thus be considered an important component of SDM.

Goal setting as a component of SDM
The clinicians, who considered goals and/or goal setting to be a component of SDM, emphasised several aspects in their descriptions. Goals and the goal setting process were described as providers of input for the decision-making process, as illustrated by the following quotation.

> *Once you have gained, let's say, insight into the patient's goals and the doctor's possibilities, then you can reach a decision. (...) In the process of exchanging information, the patient is already telling you about how they lead their life, about their goals, wishes and desires, etc. And (...) what they want to do with those. (CG_07)*

Furthermore, goals and goal setting can be seen as core components of SDM reflecting the essence of an SDM approach, as explained by one of the clinicians:

> *If you opt for shared decision-making, I think you should start with looking at what the actual goal is: 'What is the patient's goal?' (...) I believe that is what the entire process of shared decision-making is about. (CG_11)*

Or as one of the clinicians described:

> *I believe that you cannot take common decisions if you do not have joint goals. (CG_16)*

In this sense, goals and goal setting reflect a person centred attitude. Person centred care is defined as health care that is 'respectful and responsive to individual patient preferences,

needs and values and ensures that patient values guide all clinical decisions' [39]. SDM can be seen as fundamental to PCC [40], and both comprise the element of the explicit patient involvement of care [41 42].
Furthermore, the integration of the processes of CGS and SDM was emphasised. According to some of the clinicians, CGS and SDM can be viewed as an integrated process that cannot be separated: decision-making also involves goal setting. The patient and clinician jointly determine which goals are relevant and what steps to take in pursuing those goals:

> *When you ask someone: 'How do you think about your life and what do you find most important?', and it turns out that 'continue living independently' is the most important, then it makes sense that the patient is involved in thinking about the 'smaller' goal that is linked to this (...) and that they also give the green light to this... for example, by asking 'Are you okay with this? And if you're not okay with THIS, how would you feel about THAT?' This is all interwoven and cannot be seen separately. (GP_20)*

This general practitioner seems to refer to varying types of goals. Independence can be seen as a value and 'continue living independently' as a goal incorporating this value. This goal setting process could be interpreted as a process of goal setting of several related goals integrated in a decision-making process. In the view of some clinicians goals can actively steer the options presented to a patient, as illustrated by the following quotation:

> *If someone says: 'I want to continue living independently as long as possible', well, then perhaps those treatment options must be chosen that enable the patient to do this. Very invasive options, meaning for example that a patient has to travel back and forth constantly, are then excluded. (...) It means you choose the more pragmatic option. (...) Yes, I do believe that such goals give direction to the options. So if you know those goals in advance and you know what the patient wants, it becomes easier to give better advice about what the best option is. (CG_03)*

This value-driven goal of 'continue living independently as long as possible' steers the relevance and weighing of certain options in the decision-making process.

Perceptions of clinicians not mentioning goal setting as component of SDM.
Seventeen clinicians did not explicitly mention goal setting as component of a SDM approach. Our analysis revealed that not explicitly mentioning goals when attempting to do SDM does not automatically mean that there is a lack of awareness regarding goals. First, some clinicians who did not mention goals explicitly focused on aspects of patient

involvement, like 'agreement' or 'decision maker' in their description of the concept of SDM. Clinicians that did not explicitly mention goal setting or goals mentioned that aligning decisions with a patient's preferences is essential:

> *In any case, to align our thoughts. (...) to make my plan clear to the patient or ask what they still want. (...) and check (...) if the patient understands what I mean, as a GP, with a certain proposal. (GP_13)*

We can interpret these aspects of patient involvement as elements of a person centred attitude. In this sense the attitudes of these clinicians mentioning or not mentioning goal setting need not to be different. As was also concluded by Knight et al., the concepts of values, goals, and preferences are often used interchangeably [43], which could thus be a reason for part of clinicians not to mention goals or goal setting. Next to the use of other terminology, part of clinicians not mentioning goal setting when defining SDM, view CGS and SDM as separate but related processes. Some of them see CGS and goals as fundamental and SDM as a related, though more concrete, process of decision-making:

> *[SDM and CGS] is a different story, of course. Yes, because when you set a goal, you ask 'What is important to you?' (...) 'When you think of the next couple of years, what is it that you want or don't want?' And decision-making simply means that you involve the patient in the choices that you make. (...) And (...) that you provide the information the patient needs to oversee things and (...) that you try to reach a satisfactory result together. (...) But that is just a little bit different. (...) Yes, I think decision-making is bigger than that. (...) And (...) to reach a decision together, that also serves that joint goal, now doesn't it. (GP_17)*

Although viewed as separate processes, from this perspective CGS remains to be a key input to a SDM process.
Six of clinicians not mentioning goal setting explicitly, were CGs and 11 were GPs. This means that in this sample GPs in contrast to CGs in majority did not mention goal setting as a component explicitly.

Discussion

Goal setting is not widely recognised as a core component of SDM yet. Our interviews with experienced general practitioners and geriatricians indicate a need for shared decision-making approaches that explicitly and unequivocally include the task of goal setting, thereby supporting recent theoretical insights, that patient goals and the work of goal

setting can be regarded as a fundamental part of a shared decision-making process, especially when patients have multiple long-term conditions which require trade-offs between treatment options.

This study has some methodological strengths. First, considering reflexivity, we worked with an interviewer who is trained as a GP, which may have encouraged the participants to speak frankly and directly from their own professional perspectives. The second coder of the first phase was experienced in interview analysis but has no medical background. The second data analyst of the second phase (MF) is an expert on SDM, but has no background in practicing medicine. These distinct professional backgrounds helped us avoid a 'medical' bias in our data interpretation. Second, we used a purposive sampling and snowball extension method to recruit professional experts. In the Netherlands, both GPs and CGs provide medical care to older people living at home, but they do so in different settings, namely community- and hospital-based, respectively. In this stage of theory development, we considered their work to be complementary, and both contribute to the saturation of data collection on current medical thinking on these themes. Participants' basic characteristics showed considerable variability and comparability in line with the Dutch context (e.g. in case of practice type). Third, we chose a framework analysis method. This method is very suitable for analysis which departs from a theoretical position. In our analysis we used a SDM categorisation matrix based on Makoul et al.'s integrative model of SDM.

This study also has some limitations. We aimed to focus the interviews on care for a population with complex health care demands and introduced this to the interviewees by referral to criteria of age > 75 years and multimorbidity. Ideally, in the context of condition and functioning, we would have been able to specify this potential complexity further by also including factors like disease severity and disability [44]. However, we assumed that this would complicate the interviews too much, if this would be taken too literally. Patients and/or caregivers were not interviewed as part of this research. Because of the intended patient participation and patient orientation of care, interviewing patients and caregivers about these topics should be part of further research. Furthermore, in our sample we found a difference between GPs and CGs in mentioning goal setting. We have no reason to believe that GPs are less patient-oriented than CGs. Based on a qualitative focus group study of Dutch GPs, Luijks et al. [4], reported that GPs agreed to involve their patients' perspectives and preferences in the decision-making process. Further research is necessary whether this indication of possible differences in perceptions between GPs and CGs can be confirmed and if so, what causal factors could be relevant in explaining this potential difference. In addition, we used descriptions of the concept of SDM which were given spontaneously for the analysis of mentioning of the component of goal setting. Finally, although the interview guide started with the topic of SDM, all topics, including CGS, were mentioned in the introduction of the interviews. This could have primed the interviewees.

Although there is still a relative lack of tools and evidence for the effects of goal setting with older patients with chronic disease or multimorbidity [29], based on our findings, we want to make a plea to integrate explicit goal setting into a SDM approach for older patients with multimorbidity for three reasons. These are: 1. Confirmation of the inclusion of goal setting as essential component, 2. The need for consistent terminology and 3. The need for further development of practical approaches of goal setting within SDM.

First of all, our findings confirm recent theoretical insights on the relevance of the inclusion of an explicit goal setting component in a SDM approach. Sixteen of 33 clinicians interviewed mentioned the goal setting component when defining a SDM approach. This number of interviewees is comparable to the mentioning of the other main elements, namely 'Patient values/preferences' (n=16), 'Doctor knowledge/recommendations' (n=19) and 'Make or explicitly defer decision' (n=19). Furthermore, the interpretation of the descriptions of goal setting revealed that the interviewees mentioning goal setting, consider this to be an important component.

A need for consistency in terminology is a second reason for the inclusion of a goal setting component in a SDM approach. As our findings indicated clinicians seem to use different terms. This is in line with other research, which confirms that the concepts of values, goals, and preferences are often used interchangeably [43]. Clearly defining these concepts and their relevance within a SDM approach will contribute to further development of consistent theoretical models and practical approaches. In our view special attention should be given to defining types of goals in the goal setting process as our results indicated that clinicians may set and use varying types of goals.

The third reason for our plea is the need for further development of practical approaches of goal setting within SDM. Clinicians have increasing interest in goal-oriented care, especially in caring for patients with multimorbidity [1 7 8 11 14 45 46]. A goal-oriented approach in decision-making can be helpful in personalising care to accommodate patients' goals, preferences and resources [13 14]. As argued in the introduction in daily practice of caring for older patients with multimorbidity CGS is just evolving. Incorporating patient values, preferences and circumstances is a difficult step in the decision-making process [47]. Health-related goals arise not only from health but also from other dimensions like social context or wellbeing [1 13 14 45]. Clinicians may struggle to help people prioritise their values, define treatment goals and frame preferences in ways that are clinically relevant and personally meaningful (aligned with one's values) when faced with multiple diagnostic and treatment options [2 48]. In our view, the integration of the component of goal setting in a model of SDM with older patients with multimorbidity is a next step to constitute a solid theoretical base for further development of practical tools which could be valuable in facing these challenges. Based on our research on the perspectives of the interviewed clinicians, the inclusion of the component of explicit goal setting *as part of* a SDM approach seems to be most promising

to synchronise concepts and approaches in caring for this category of patients.
Our research has several implications. Our findings indicate that clinicians who want to practice SDM in the complex group of older patients with multimorbidity will be greatly facilitated by explicitly integrating goal setting into this approach. Research is necessary on perceptions of patients on this topic. Furthermore, potential differences in perceptions of GPs and CGs need further research. Finally, for practical tool development, potential variation in types of goals is an important topic for further research. Integrating explicit goal setting into a SDM approach would probably increase explicitly setting goals in practice, and may lead to further tool development. Goals could aid in reaching unambiguous terminology for the patient perspective in SDM. It might also improve inter-professional communication and collaboration by offering the possibility to exchange explicit goals. In our view, awareness and integration of goal setting in SDM could be beneficial for all patient categories, although benefits may vary. We assume that the more complex decision-making becomes, the more beneficial explicit goal setting will be.

Conclusions

Our study on clinicians' perspectives showed a lack of explicit goal setting as component of a SDM approach. We conclude that a comprehensive model for SDM with older patients with multimorbidity should be developed further by including explicit goal setting, as these are rightly regarded by clinicians as the key factor in aligning diagnostic and therapeutic options with patient preferences and values.

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Additional files

Additional file 2.1 **Consolidated criteria for Reporting Qualitative Studies (COREQ)**

Item	Answer
DOMAIN 1: Research team and reflexivity	
Personal characteristics	
1. Interviewer/facilitator	First author
2. Credentials	MD, MSc
3. Occupation	Senior advisor at an advisory council on public health and health care (public service) and PhD student.
4. Gender	Female
5. Experience and training	Economist and former general practitioner. PhD student. Courses on Atlas-ti and qualitative research.
Relationship with participants	
6. Relationship established	The sampling of potential participants was initiated by interviewing a GP and CG, who were both acquaintances of the interviewer; the other participants were not.
7. Participant knowledge of the interviewer	Former general practitioner. Interviews belonging to PhD research.
8. Interviewer characteristics	She has a background as a GP and an affinity for geriatric care. Considering working with an interviewer who is trained as a GP may have encouraged the participants to speak frankly and directly from their own professional perspectives. The second coder of the first phase has substantial experience in interview analysis but has no medical background, which helped us avoid a 'medical' bias in our data interpretation. The second coder of the second phase is an expert on shared decision-making but has no background in practicing medicine.
DOMAIN 2: Study design	
Theoretical framework	
9. Methodological orientation -and theory	Framework analysis
Participant selection	
10. Sampling	A purposive and snowball method aiming to recruit professional experts.
11. Method of approach	By email. Part of the recruitment of GPs took place at a broader meeting of GPs specialised in geriatric care.
12. Sample size	33 (18 clinical geriatricians and 15 general practitioners)
13. Non-participation	The response rates of clinical geriatricians and general practitioners were 86% and 54% respectively. Of the 21 CGs approached, one CG refused and two CGs did not respond to the first and reminder emails. A total of 28 GPs was approached. There were 6 non-responders. 3 GPs responded positively, but did not respond to proposed dates. There were two drop-outs (the interview was cancelled and there was no rescheduling (i.e. no response to proposed dates)). Two GPs of the same practice chose one participant. Their lack of time was the main reason not to participate.
Setting	
14. Setting of data collection	Five interviews were face-to-face, the others were held by telephone, as the medical practitioners' busy schedules and varying locations required flexibility. The face-to-face interviews were held at the interviewee's office.

Item	Answer
15. Presence of non-participants	No
16. Description of sample	See Table 2.1 Basic characteristics of participants
Data collection	
17. Interview guide	Main topics and subtopics are provided in Additional file 2.2. A more detailed interview guide (in Dutch), including the introduction and closing of the interview, the specific questions on the topics and questions on basic characteristics, is available upon request. In one case, the interview guide was sent to the interviewee in advance of the interview.
18. Repeat interviews	No
19. Audio/visual recording	Audio-recording of all interviews
20. Field notes	Yes
21. Duration	Approximately 1 hour
22. Data saturation	Yes
23. Transcripts returned	3 interviewees wanted to receive the transcripts, which they did.
DOMAIN 3: Analysis and findings	
Data analysis	
24. Number of data coders	2
25. Description of the coding tree	The coding tree of the first phase of analysis is available upon request. The categorisation matrix (second phase) is reported.
26. Derivation of themes	A framework approach was used for data analysis in two phases. In the first phase, we used open coding. The first five interviews were coded independently by two data coders (NV, MH). Initial codes were compared, discussed, grouped and categorised in order to determine a working analytical framework. Remaining interviews were coded by one researcher (MH) and checked by the other (NV). In weekly meetings, the researchers (NV and MH) compared, discussed and agreed on the coding of the transcripts, including the creation of additional codes and further refinement of analysis. In the second phase of analysis, we further analysed the theme 'SDM concept' and theme 'Links between the concepts of SDM and CGS'. For this purpose, we used a SDM categorisation matrix based on the essential, ideal and general elements of Makoul et al.'s integrative model of SDM, shown in Box 2.1 [18]. We added a new category to this SDM categorisation matrix: goals/goal setting. We charted the data in this categorisation matrix and findings were interpreted.
27. Software	Atlas-ti 7.1.15
28. Participant checking	Two participants provided feedback upon request.
Reporting	
29. Quotations presented	Yes
30. Data and findings consistent	Yes
31. Clarity of major themes	Not applicable
32. Clarity of minor themes	Not applicable

Note: Consolidated Criteria for Reporting Qualitative Studies (COREQ): A 32-item checklist [35]

Additional file 2.2 **Main and subtopics of the semi-structured interview guide**

Main topics	**Subtopics per main topic**
Introduction of the interview	
Collaborative goal setting between medical practitioners and patients	Definition of the concept Experiences and process description Types of goals Barriers and facilitators
Collaborative goal setting within a collaborative framework of multiple medical practitioners	Experiences and expectations Roles Barriers and facilitators
Shared decision-making between medical practitioners and patients	Definition of the concept Experiences and expectations Barriers and facilitators
Shared decision-making within a collaborative framework of multiple medical practitioners	Experiences and expectations Roles Barriers and facilitators
Effective collaborative action between multiple medical practitioners	Definition of the concept Experiences and expectations Roles Barriers and facilitators
Relationships between the examined concepts of collaborative goal setting, shared decision-making and effective collaborative action	Relationships between the concepts Desirability of these processes Possible actions to stimulate
Conclusion of the interview	Conclusion of the interview

Note: Additional file 2.2 provides an overview of main and subtopics of the semi-structured interview guide

CHAPTER 3

A three-goal model for patients with multimorbidity: A qualitative approach

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Abstract

Background: To meet the challenge of multimorbidity in decision-making, a switch from a disease-oriented to a goal-oriented approach could be beneficial for patients and clinicians. More insight about the concept and the implementation of this approach in clinical practice is needed.

Objective: This study aims to develop conceptual descriptions of goal-oriented care by examining the perspectives of general practitioners (GPs) and clinical geriatricians (CGs), and how the concept relates to collaborative communication and shared decision-making with elderly patients with multimorbidity.

Method: Qualitative interviews with GPs and CGs were conducted and analysed using thematic analysis.

Results: Clinicians distinguished disease- or symptom-specific goals, functional goals, and a new type of goals, which we labelled as fundamental goals. 'Fundamental goals' are goals specifying patient's priorities in life, related to their values and core relationships. These fundamental goals can be considered implicitly or explicitly in decision-making or can be ignored. Reasons to explicate goals are the potential mismatch between medical standards and patient preferences and the need to know individual patient values in case of multimorbidity, including the management in acute situations.

Conclusion: Based on the perspectives of clinicians, we expanded the concept of goal-oriented care by identifying a three-level goal hierarchy. This model could facilitate collaborative goal setting for patients with multiple long-term conditions in clinical practice. Future research is needed to refine and validate this model and to provide specific guidance for medical training and practice.

Introduction

Interest in goal-oriented care is increasing among policy makers and clinicians alike [1-7]. Goal-oriented care is particularly important where patients have multiple long-term conditions, known as multimorbidity. Multimorbidity is defined as the coexistence of two or more chronic diseases or conditions, and its incidence is causing a challenge to health care systems, patients and medical practitioners. In daily medical practice, multimorbidity challenges decision-making in several ways. Disease priorities can be interfering [8 9] and the need of adherence to multiple disease guidelines can be problematic [10]. Disease-specific guidelines are often not applicable to older patients with multiple conditions [7 9 11 12] and compliance to multiple single disease guidelines can result in polypharmacy, high treatment burden, inattention to social and personal context and failure to align care with personal goals and preferences [13 14]. Having multiple chronic conditions often leads to the involvement of several clinicians, who concentrate on managing different conditions and monitoring different disease-specific outcomes. Patients are at risk of receiving fragmented care that might lack focus on what matters most to them [7]. Focusing care on what matters most to patients could be helpful but is also a challenge in itself.

Aligning health outcomes with individuals' values is complex, especially for older adults with multiple chronic morbidities facing conditions with clinical uncertainty (e.g. cancer) [15-17]. Clinicians are challenged in helping people prioritise their values, define treatment goals and frame preferences in ways that are clinically relevant and aligned with one's values when faced with multiple diagnostic and treatment options [18 19]. Patients and clinicians may also differ in perspectives and priorities in this respect [6 9 16 19-22]. Clinicians are at risk to make inaccurate assumptions about patient values and preferences [3] and may think that they know what is best for patients [10]. It is clear that in care for older patients with multimorbidity, incorporating values and preferences in decision-making is necessary to focus on what matters most to them, but in daily practice this is complex.

To meet the challenges of multimorbidity care, including the necessary incorporation of values and preferences, Tinetti et al. [2] proposed a shift from a disease-oriented to a goal-oriented approach. Taking this approach, it seems health goals can be defined using a range of dimensions (e.g. symptoms; physical functional status, including mobility; and social role). In goal-oriented health care, care is personalised to accommodate patients' goals, preferences and resources [3 23]. Collaborative goal setting (CGS), defined as 'a process by which health care professionals and patients agree on a health-related goal' [15], can be useful for personalising care and encourages patient involvement in the goal setting process. CGS has been evaluated in several rehabilitation settings [24-27]. However, CGS in the context of older patients with multimorbidity is not common practice yet. In the 2014 Commonwealth Fund Survey of adults aged 65 or older and having a chronic condition,

rates of respondents reporting the sharing of goals with a professional varied from 23% (Sweden), till 59% (United Kingdom). Nine of 11 countries were having rates of less than 50% of respondents reporting the sharing of goals with a professional [28]. There appears to be a relative lack of insight in goal setting processes in the presence of complexity and little evidence to support best practices in goal setting with complex patients [29]. Furthermore, as concluded by Knight et al., the concepts of values, goals and preferences are often used interchangeably [30], indicating a need for establishing consistent definitions. In the Netherlands, the current views of general practitioners (GPs) and clinical geriatricians (CGs) on the concepts of goals and collaborative goal setting are as yet unknown. These views could provide valuable input into the concept of goal-orientation and into the perceived relevance of the approach in clinical practice. The objective of this study was to examine the concept of goal-orientation from a clinician's perspective, in the context of CGS and shared decision-making (SDM), where patients have multiple long-term conditions.

Method

Participants

This qualitative study was conducted by inviting CGs and GPs to participate in semi-structured interviews. Participants were selected using a purposive and snowball method, aiming to recruit professional experts, and contacted by email. We invited experienced GPs and CGs performing research, teaching, developing or implementing specific innovations in care for older patients. The first two participants were acquaintances of the interviewer (first author). Some GPs were recruited at a meeting of GPs holding a specialization in geriatric care. In the sampling we aimed to recruit comparable numbers of CGs and GPs. To obtain diverse perspectives we tried to ensure that different types of practice and practice location (rural or urban) for GPs and different types of hospitals (CGs) would be represented. Furthermore, we tried to ensure that all Dutch regions would be represented as much as possible. The response rates of CGs and GPs approached were 86% and 54%, respectively. The final sample consisted of 18 CGs and 15 GPs.

Procedures

An interview guide (Table 3.1) was inspired by two perspectives on goal-oriented health care for elderly patients with chronic multimorbidity [2 3] and professional experiences (general practice and clinical geriatrics) in our research team. Two pilot interviews were conducted with a CG and a GP. Main topics and subtopics were not changed based on the pilot interviews nor during the conducting of the interviews. The interview guide covered three main topics: CGS, SDM and effective collaborative action. We defined *effective collaborative*

action as clinicians and patient deciding on and performing diagnostic and treatment steps in line with collaborative goals, which were set between patient and clinicians or with other involved caretakers. Definitions were not given to the interviewees. At the start of the interview, the clinicians were asked to use the context of regular care for community dwelling older patients (age >75 years) with a chronic disease or multimorbidity without further specifications. It was also suggested to keep one or more cases in mind in answering the questions. All topics and subtopics were covered in all interviews. Interviews could differ in asking further questions for a better understanding of an interviewee's answer.
The first author, who is trained as a GP, conducted the interviews between November 2012 and April 2013. The interview duration was approximately 60 minutes and they were conducted face-to-face or by telephone. All interviews were audio-recorded and transcribed. Detailed field notes were made after each interview. Theoretical memos were drafted throughout the data collection and analysis process. The two final interviews confirmed theoretical saturation as they did not reveal new issues or topics.

Table 3.1 **Main topics of the semi-structured interview guide**

Main topics	Subtopics per main topic
Introduction of the interview	
Collaborative goal setting between medical practitioners and patients	Definition of the concept Experiences and process description Types of goals Barriers and facilitators
Collaborative goal setting within a collaborative framework of multiple medical practitioners	Experiences and expectations Roles Barriers and facilitators
Shared decision-making between medical practitioners and patients	Definition of the concept Experiences and expectations Barriers and facilitators
Shared decision-making within a collaborative framework of multiple medical practitioners	Experiences and expectations Roles Barriers and facilitators
Effective collaborative action between multiple medical practitioners	Definition of the concept Experiences and expectations Roles Barriers and facilitators
Relationships between the examined concepts of collaborative goal setting, shared decision-making and effective collaborative action	Relationships between the concepts Desirability of these processes Possible actions to stimulate
Conclusion of the interview	Conclusion of the interview

Analyses

Inductive thematic analysis was used for analysis [31]. Thematic analysis is an approach for qualitative research focusing on identifying, analysing and reporting patterns (themes) within qualitative data and the interpretation of aspects of the research topic. In an inductive

approach, themes are data-driven. An iterative process of interviewing and analysis was followed. During the interviewing phase, preliminary analyses were conducted based on reflections and discussion of the interviews (first and last author) and by constantly comparing the interviews with the field notes. These preliminary analyses were conceived in theoretical memos, and the interview guide was continually adapted to reflect emerging insights.

In the coding process, data were conceptually interpreted and labelled accordingly. The two data coders (first and second author) applied open coding to the first five transcripts. Initial codes were compared, discussed, grouped and categorised in order to develop an initial coding tree. The first five interviews were coded independently by both data coders. The remaining interviews were coded by one researcher (second author) and checked by the other (first author). In weekly meetings, the researchers (first and second author) compared, discussed and agreed on the coding of the transcripts, including the creation of additional codes and further refinement of categories and subcategories. Similarities, differences, regularities and patterns were interpreted and discussed to identify themes and to generate hypotheses. Illustrative quotations were selected to underpin and illustrate our findings. In addition, Box 3.1 presents two case examples, one of a GP and one of a CG to illustrate daily practice of this topic.

Box 3.1 **Two case examples from daily practice**

Case example one

GP_10 spoke about a patient of over 90 years old whose hip surgery had failed.

[The prosthesis] got infected, so her hip had to be removed (…) She was admitted to a nursing home (…), but she really wanted to return home. I understood why, because she had an unusual background. She had been interned in a concentration camp years before that (…). All she really wanted was to go home, because that was the only place she felt safe (…). Everything around her reminded her of her traumatic experiences (…). She actually returned to her apartment in that severely disabled state. But she coordinated all her care and assistance there (…) and lived for years, in fact. Naturally, this is an extreme case, but if you look at the patient's circumstances and history, it is completely understandable (…) and her final years were wonderful. Yes, they were.

Case example two

CG_11 spoke about a patient who was referred by the general practitioner because of abdominal pains, whereas this patient had been screened by the internist three years earlier revealing no major diseases.

The GP still was not sure: Couldn't there still be a malignancy, isn't there anything else still? He did not have a conversation with the patient asking: 'If we refer you to that hospital now, what would be your goal? And what is your goal in life in general?' (…) I came to an agreement with (…) the patient: 'OK, we are going to do some examinations' (…), but we also immediately talked about: 'What would you actually want?' And then she said: 'I really just want the abdominal pains to go away' (…) She was very clear about her concerns: 'It is not my main concern whether there is a malignancy or not.' (…) Then you talk it over in a conversation with the patient. If you've set that goal for yourself: 'Now, how far do we want to go to see if we can help you get there?' And together you decide that, at this moment, a colonoscopy and a gastroscopy are really too much for the patient. And yes, a patient then accepts that certain issues cannot be completely figured out. But we do as much as we can to help her achieve her goals.

Note: These are two case examples from daily practice that show the importance of aligning care with patients' personal history, values and priorities and its difficulties.

The quotations were translated from Dutch into English by a professional translator. The translator and first author discussed the translations to ensure that proper meaning of words and nuances were kept in the translation process. For data coding and analysis, Atlas-ti 7.1.15 (GmbH, Berlin, Germany) software was used.

Quality Assurance

The Consolidated Criteria for Reporting Qualitative Research (COREQ) and a 15-point checklist for thematic analysis by Braun and Clarke were used for design, performance and reporting [31 32]. Additional file 3.1 reports on these COREQ criteria in relation to our research. All interview topics were analysed in one process in order to secure consistency and theoretical interrelatedness.

Results

Participating GPs' (n=15) mean age was 51 years, being 40% male and on average having 16 years of professional experience. Participating CGs (n=18) had a mean age of 48 years, being 50% male, and having on average 10 years of professional experience. Further participants' characteristics are presented in Table 3.2.

Table 3.2 **Basic characteristics of participants**

Characteristics	**General practitioner n=15**	**Clinical geriatrician n=18**
Age, *M* (SD)(years)	51 (6.6)	48 (8.6)
Gender, *n* (% men)	6 (40)	9 (50)
Practice type, *n* (%)		N/A
Single	1 (7)	
Duo	2 (13)	
Group/Health centre	12 (80)	
Physician assistant in geriatric care*, *n* (% yes)	12 (80)	N/A
Type of hospital, *n* (%)	N/A	
Academic centre		3 (17)
Community hospital		9 (50)
Mental care facility		2 (11)
Non-academic teaching hospital		4 (22)
Researcher, *n* (% yes)	5 (33)	9 (50)
Supervisor, *n* (% yes)	3 (20)	11 (61)
GP specialised in geriatric care, *n* (% yes)	9 (60)	N/A
Years of professional experience, *median* (range)	16 (3 - 34)	10 (3 - 22)

Note: N/A = not applicable; M= mean; SD= standard deviation; GP= general practitioner
*in GP practice

Three themes were identified (Box 3.2):

Box 3.2 **Themes**

- Clinicians draw distinctions between different types of goals, namely disease-specific or symptom-specific goals, functional goals, and fundamental goals.
- The consideration of fundamental goals.
- The relevance of explicit goals for decision-making.

Clinicians draw distinctions between different types of goals

From the data, three types of goals were identified, that is disease-specific or symptom-specific goals, functional goals and a third category labelled as fundamental goals.

Fundamental goals were described as goals specifying a patient's priorities in life, such as their values and core relationships, topics that serve as reference points for decision-making. These are goals considering the patient's personal views on what constitutes quality of life. Fundamental goals concern questions such as: 'What makes your life worth living?'; 'How do you lead your life?'; 'What are your views on end of life?'; 'How do you feel about quality of life vs. lengthening of life?'. Examples provided by medical practitioners include: 'being of help to others and/or society', and 'no wish for changes'. 'Being able to continue living independently' is a goal often mentioned by patients, according to medical practitioners, for example CG_29:

> *Almost invariably, the main goal for this target group is to continue living independently (…) And that ability to continue living independently is frequently more important to [patients] than being treated in a residential care facility or nursing home. (CG_29)*

Fundamental goals reflect a patient's view on their own future in the broadest sense.

Functional goals were described as goals related to reducing limitations in functioning. Examples include 'being able to wash or dress oneself', 'driving a car', and 'staying mobile'. GP_06 described functional goals as follows:

> *What is important and what should we focus on? (….) Is it an issue if people are only able to go to a convenience store or supermarket? Or is the problem that they can no longer shop or dress independently? (GP_06)*

Disease-specific or *symptom-specific goals* are goals relating to the diagnosis or treatment of a specific disease or symptom. Patients may ask for example for the reduction of distress caused by symptoms like shortening of breath, itching or pain. In a goal setting process, clinician and patient can set a patient symptom-specific goal together, which incorporates

personal choices in diagnostic trajectories and treatments. Some patients, for example, do not want to engage in all kinds of diagnostic trajectories as long as a certain symptom can be reduced by a certain symptomatic treatment. Other patients want to know what is causing the symptom. This type of goals can also originate from a certain disease. An example is a patient asking for disease-specific medication, as mentioned by CG_21:

> *These goals vary largely per patient. They can be very explicitly related to the disease. Conceivably, for instance, a patient may make a very specific request for 'a pill against dementia'. (CG_21)*

The consideration of fundamental goals

The practitioners differed in their consideration of fundamental goals, creating three orientation categories, that is: 1. No consideration of fundamental goals, 2. Implicit consideration of fundamental goals, and 3. Explicit consideration of fundamental goals.

No consideration of fundamental goals

Practitioners in this category mentioned a primary focus on functional goals and/or disease-specific or symptom-specific goals. Functional goals and disease-specific or symptom-specific goals can be connected to each other as described by CG_12:

> *Those [patients] usually come to me with problems (…). Their complaints vary from 'more trouble walking' to 'tiring out faster', 'forgetfulness', 'falling' and a whole range of other problems. You try to unravel all their problems and often come back to their medical diagnosis. At that point, you try to figure out how you can help. But the foundation is still the patient's functioning (…). (CG_12)*

The practitioners in this category did not mention setting or taking into account fundamental goals.

Implicit consideration of fundamental goals

Practitioners in this category were aware of fundamental goals. However, these goals were presumed but not made explicit in a discussion with the patient. GP_04 illustrates that they are aware of implicit fundamental goals while focusing on quality of life:

> *At present, what I really find important is that we mainly focus on the quality of life of the elderly and take into account their opinions and preferences. In terms of actual practice, I cannot say that my colleague and I have specific discussions [with our patients] on a regular basis about the goals patients want to pursue in their life. However, based on the questions*

asked, we do pay attention to what is feasible for patients. We are also cautious when it comes to adding any new medicine, having in mind the issue of multiple medications and their side effects. It is a matter of weighing up everything very carefully. When it comes to elderly patients, it is important to figure out whether all interventions will benefit them. (GP_04)

Explicit consideration of fundamental goals

The third category constitutes practitioners who have an orientation towards disease-specific and/or functional goals, while explicitly taking fundamental goals into account. If fundamental goals are discussed and made explicit, other goals can be set in accordance with these fundamental goals, as illustrated by the following example from daily practice of the importance of quality of life as a reference point in decision-making. What quality of life means to a specific patient, can only be assessed by that specific patient:

Now imagine I discover that someone has cancer and maybe I can still help them (…) in a way that allows the patient to live a few months longer. But then, of course, there is still the decision whether or not to treat him (…). Or do you choose limited treatment? That is something that must be agreed upon with specialists, the patient and, of course, with me (…) The core issue remains the quality of life. And (…) of course that is something I can assess, at least to a certain extent, but this will primarily be done by the patient. (GP_10)

This theme 'The consideration of fundamental goals' makes clear, that although aspects of implicit fundamental goals may be taken into account, discussion and consideration of aspects of explicit fundamental goals, are not regular practice yet. Table 3.3 provides several quotations of questions asked to elicit fundamental goals, as mentioned by the practitioners. These practitioners' examples were transformed by the authors into possible questions, which may be helpful to use in clinical practice to start a discussion on fundamental goals.

The relevance of explicit goals for decision-making

The analysis revealed several reasons to explicate fundamental goals. The patient's preferences are not always in line with medical standards, nor with the preferences of the practitioners involved, as is illustrated by CG_03:

I really do believe that care will become better for the patient, that they will finally get the care they want instead of the care that guidelines or we together, say they must be given, whereas that is not what they want. (CG_03)

Secondly, patients' preferences may vary. For example, CG_17 describes differences in medication preferences in a case of dementia:

> *Some people are keen to try this medication which might improve their memory (…) But there are also people who say: 'If it leads to weight loss or gives me skin problems, then I don't want it'. (CG_17)*

In the event of multimorbidity, the consideration of goals is even more important. The more complicated a patient's situation, the more important it is to incorporate what constitutes quality of life to a patient in decision-making as described by GP_28:

> *The more complicated the situation, that is the more medical issues someone is suffering from, the more the focus lies on quality of life and on the interaction between various conditions and what that means to someone (…). Then, it becomes more important to know what patients want for themselves, as it is important to have ideas about that (…). So basically, the larger the extent of multimorbidity, the more important it is to know what is important to the patient. (GP_28)*

A discussion of fundamental goals can be helpful to make this meaning of quality of life, what people want for themselves in a broader sense and what is important to someone, explicit. Finally, discussing fundamental goals explicitly can provide important information for acute situations that may occur in the future, as is emphasised by CG_14:

> *When it comes to vulnerable elderly people, the circumstances that require you to make important decisions often arise unexpectedly (…). This may happen, for instance, when their regular doctor is absent and a different doctor is on duty (…) or by an emergency doctor in the hospital (…). When these situations occur, it is really helpful to be able to rely on information you have exchanged earlier on. (CG_14)*

Table 3.3 **Example questions for collaborative fundamental goal setting**

Example questions	Quotations
How do you see your future? How would you prefer to plan it?	GP_15: I mean, you have to consider how these individuals see their future (…) and how they prefer to shape that future....
Where are you from and to what extent does spirituality play a role in your life? How do you feel about the different aspects of your life? How do you envision the end of your life?	GP_21: On the one hand, I ask everyone over 75 about their core values and quality-of-life values. As for the extent of their spiritual experiences, and where they come from (…) We are not in a position to deal with that (…). Regarding quality-of-life values, those tend to relate to things like whose children visit first or (…) whether the garden is still blooming, etc. (…) Based on the core values and quality of life and other [things], we can retrieve a clear picture. At any rate, there is a lot of similarity. Is advance care planning more of a medical process? (….) If so, how do you start your daily life and how exactly do you end it? (….) When do you want that to happen? (….) This is what the patients' vision of the end of their life entails (…) in terms of core values and quality-of-life values.
What is important to you? What do you want and what do you want to avoid? What do you consider important? What are you afraid of?	CG_17: 'What do I find important?'; 'What do you really want and what do you want to avoid?' (…) 'What do you consider important?'; 'What are you afraid of?'
What are your goals and what do you want from life, specifically?	GP_10: 'What are your goals and what do you want from life, specifically?' This question is obviously very essential. The first things that come to mind, of course, are end-of-life decisions, such as entering a nursing home, continue living independently, undergoing euthanasia or refusing it. That period, however, is just one aspect, and it comes at the very end. Before that point, there is so much more: decisions about how to live and whether or not to accept medical treatment. So, the decision-making process concerns treatment, referral, end of life and place of residence.

Note: The example questions are based on illustrative examples given by the interviewees.

Discussion

Main findings

The case examples (Box 3.1) demonstrate the importance and difficulties of aligning care with patients' personal histories, values and priorities. Our analysis revealed three types of goals: disease-specific or symptom-specific goals, functional goals, and a third type of goals, which we labelled fundamental goals. From our analysis followed, that fundamental goals are implicitly and explicitly applied in daily practice. We hypothesise that the explicit setting and application of fundamental goals could lead to patient-specific clinical decisions concerning diagnostic trajectories or treatments by translating values, personal history and core relationships into useable reference points for decision-making.

Interpretation

Earlier studies confirmed our findings. Maintaining (functional) independence, fixing specific symptoms or functional challenges, day-to-day functioning, behaviour and emotional health and safety are considered important goals and priorities [33 34]. An analysis of health-related values of multimorbid cancer survivors revealed the five values: self-sufficiency, life enjoyment, connectedness and legacy, balancing quality and length of life, and engagement of care [18]. Incorporating patient values into health care decisions is critical, especially for elderly patients since goals may change when life expectancy shortens [35]. However, there appears to be a lack of consistency in the use of the concepts of values, goals and preferences [18 30]. Naik et al. [18] make a distinction between values and health care goals, whereby goals and preferences are seen as more context or circumstance specific. Values usually are stable and can be seen as fundamental beliefs about one's self and life. Our findings are consistent with the importance and guiding role of values, as stated by Naik et al. [18] However, although most people would intuitively agree with the importance of incorporating values in decision-making, this seems to be not an easy 'job'. Insight in approaches to actually clarify values and elicit patient preferences in a structured and consistent manner is lacking [36].

As a synthesis of the three themes identified from the data, Figure 3.1 represents a three-goal model for clinical practice showing three levels of relevant goals in caring for elderly with multimorbidity. Within this three-goal model, types of goals are interrelated, with disease-specific or symptom-specific goals flowing from functional goals, and both flowing from fundamental goals. Symptom-specific goals, for example, incorporate personal choices in diagnostic trajectories and treatments. These personal choices are based on aspects like beliefs, personal history, core relationships, values and functioning. Explicit fundamental and functional goals represent these aspects and are thereby useful in the related goal setting process of symptom- or disease specific goals.

Figure 3.1 **Three-goal model for clinical practice**
This figure shows that disease-specific or symptom-specific goals flow from functional goals and both flow from fundamental goals.

Fundamental goals can be seen as a translation of elements like values, core relationships and priorities in life, into concrete goals. If, for example, both autonomy (quality of life at home above prolonging life in a nursing home) and staying with and taking care of your disabled child as long as possible, are important to a person, this conflict and / or trade off in these important values / life goals / core relationships can be discussed and translated into a fundamental goal. For example, a fundamental goal could be to prolong life as long as possible, even with the chance of having to stay in a nursing home, provided that this person remains cognitively able to self-manage his or her life and that of his or her disabled child. In this sense, fundamental goals translate rather abstract elements such as values, acknowledging nuances and trade-offs in a certain context. Explicit awareness of all three goal levels and their interrelatedness is needed, although the emphasis on a certain type of goal in a specific care situation will be dependent on patient-specific, professional-specific and contextual factors. This three-goal model may provide a guide for collaborative goal setting and the consideration of explicit goals in decision-making with patients with multiple long-term conditions.

The three-goal model could be relevant for individualised management or care plans. In case of multimorbidity a dynamic individualised care plan is recommended [9 37-40]. Core elements of these plans are: 'optimising quality of life, eliciting preferences and goals, weighing risks and benefits of implementing recommendations from single disease guidelines, addressing trade-offs, setting priorities, stopping potentially harmful or unnecessary medications and starting beneficial medications while simplifying regimens, integrating care, and minimising treatment burden' [37]. In individualised care plans, values are seen as guiding principles. Using the three-goal model in individualised care plans may be helpful to actually use values as guiding principles. In a process of fundamental goal

setting, values are translated into explicit fundamental goals, thereby also incorporating elements as personal history and core relationships. These explicit fundamental goals can be used as input for the elicitation of the other goal types. In this way, a goal setting approach of different types of interrelated goals actually incorporates values into care plans and health-care decisions.

Berntsen et al. [40] developed a goal typology with a distinction between professionally defined and personally defined goals. Personally defined goals are goals which 'honour the patient's right to make decisions about his/her personal matters'. Personal goals 'amount to a personal construction of what 'health' means for the individual' [36]. These personal goals are used to justify the choice of the goals a professional should pursue. Our three-goal model differs from Berntsen's framework in two ways. Considering content, fundamental goals are based on and include values, aspects of personal history, individual priorities in quality of life and core relationships, thereby constituting a further elaboration on the concept of personal goals. Furthermore, in contrast to Berntsen et al., all types of goals are basically elicited jointly, although the weight of the patient's and the professional's input may vary for different types of goals. Although fundamental goals are very personal and can be difficult to construct, elicit and share, discussing and explicating these goals is a collaborative process between patient and practitioner. In our model, all types of goals are joint goals in this sense and not exclusively patient or professional goals.

It must be noted that fundamental goals and collaborative goal setting show similarities with advance care planning (ACP). ACP is a formal decision-making process that aims to support patients in making decisions about future care in anticipation of the incapacity to make decisions due to a worsening condition [41]. Patients consider the focus in health care on patient goals and values to be particularly helpful [42]. ACP is usually part of an end-of-life care strategy and is used in the context of progressive illness and anticipated deterioration [43]. In our view, discussing and explicating a patient's fundamental goals and specifying values and underlying beliefs and preferences, could also be valuable in earlier stages of life, especially in patients with multimorbidity.

Strengths and limitations

The methodological strengths of this study include the following: First, we worked with an interviewer who is trained as a GP, which may have encouraged the participants to speak frankly and directly from their own professional perspectives. The second coder has substantial experience in interview analysis but has no medical background, which helped us avoid a 'medical' bias in our data interpretation. Second, a purposive sampling and snowball extension method was used to recruit professional experts. In the Netherlands, both GPs and CGs deliver medical care to elderly people living independently, but they provide care in different settings. In this phase of theory development, we consider GPs

and CGs to be complementary, as they both contribute to the saturation of data collection on current medical thinking on these themes. We are aware, that our purposive sampling and snowball extension participant selection method has a risk of bias in the sense that the results cannot be generalised to the whole Dutch GP and CG population. However, although our selection of participants is not representative for the whole GP and CG population, these are representatives who can be considered specifically interested and busy in developing clinical practice, especially care for older patients, further. We considered recruitment of these professional experts a necessity to answer our research question, because a goal-oriented approach and CGS more specifically are not yet broadly implemented. Considering participants' basic characteristics (Table 3.2); these show considerable variability and comparability in line with the actual Dutch context, for example in case of practice type.

A limitation of the study is that the categories in the theme 'The consideration of fundamental goals' were based on data analysis of the answers spontaneously given by the clinicians. The clinicians in the first category, 'No consideration of fundamental goals', explicitly mentioned a primary focus on functional goals and/or disease-specific or symptom-specific goals. They did not mention setting nor taking the type of goals, we eventually labelled as fundamental goals into account. Based on our results, we cannot be sure that they never take fundamental goals into account in their daily patient care; however, we can conclude that fundamental goals were not their primary point of orientation, otherwise they would have mentioned (aspects of) fundamental goals. We did not ask this during the interview, because this would potentially influence the results.

A further limitation of the study is that the model was developed on the basis of practitioners' perspectives. Evaluation and adaptation of the model on the basis of an analysis of patients' and caregivers' perspectives is a high priority area. In addition, the impact of eliciting fundamental goals on the quality of decision-making and of care requires future research.

Implications for practice and research

Further research on the patients' perspectives on goals is required. Further combined theoretical and practice-based research on this topic of goal-orientation in the context of goal setting and decision-making could prepare a shift in clinical practice towards goal-oriented care for patients with multimorbidity.

Conclusion

This qualitative study provides new insights into types of goals and the consideration of goals in care for elderly patients with multimorbidity. Based on the perspectives of clinicians

we expanded the concept of goal-oriented care by identifying a three-level goal hierarchy acting as a guide to clinical care of patients with multiple long-term conditions. Awareness of and application of explicit fundamental goals in addition to functional and symptom-specific and/or disease-specific goals could contribute in making daily care more patient goal-oriented. Future research is needed to refine and validate the developed three-goal model and to provide recommendations for medical training and practice.

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Additional files

Additional file 3.1 **Consolidated Criteria for Reporting Qualitative Studies (COREQ)**

Item	Answer
DOMAIN 1: Research team and reflexivity	
Personal characteristics	
1. Interviewer/facilitator	First author
2. Credentials	MD, MSc
3. Occupation	Senior advisor at an advisory council on public health and health care (public service) and PhD student.
4. Gender	Female
5. Experience and training	Economist and former general practitioner. PhD student. Courses on Atlas-ti and qualitative research.
Relationship with participants	
6. Relationship established	The sampling of potential participants was initiated by interviewing a GP and CG, who were both acquaintances of the interviewer; the other participants were not.
7. Participant knowledge of the interviewer	Former general practitioner. Interviews belonging to PhD research.
8. Interviewer characteristics	She has a background as a GP and an affinity for geriatric care. Considering working with an interviewer who is trained as a GP may have encouraged the participants to speak frankly and directly from their own professional perspectives. The second coder has substantial experience in interview analysis but has no medical background, which helped us avoid a 'medical' bias in our data interpretation.
DOMAIN 2: Study design	
Theoretical framework	
9. Methodological orientation and theory	Inductive thematic analysis
Participant selection	
10. Sampling	A purposive and snowball method aiming to recruit professional pioneers.
11. Method of approach	By email. Part of the recruitment of GPs took place at a broader meeting of GPs holding a specialisation in geriatric care.
12. Sample size	33 (18 clinical geriatricians and 15 general practitioners)
13. Non-participation	The response rates of clinical geriatricians and general practitioners were 86% and 54% respectively. Of the 21 CGs approached, one CG refused and two CGs did not respond to the first and reminder emails. A total of 28 GPs was approached. There were 6 non-responders. 3 GPs responded positively, but did not respond to proposed dates. There were two drop-outs (the interview was cancelled and there was no rescheduling (i.e. no response to proposed dates)). Two GPs of the same practice chose one participant. Their lack of time was the main reason not to participate.

Item	Answer
Setting	
14. Setting of data collection	Five interviews were face-to-face, the others were held by telephone, as the medical practitioners' busy schedules and varying locations required flexibility. The face-to-face interviews were held at the interviewee's office.
15. Presence of non-participants	No
16. Description of sample	See Table 3.2 Basic characteristics of participants
Data collection	
17. Interview guide	Main topics and subtopics are provided in Table 3.1. A more detailed interview guide (in Dutch), including the introduction and closing of the interview, questions on the topics and questions on basic characteristics, is available upon request. In one case, the interview guide was sent to the interviewee in advance of the interview.
18. Repeat interviews	No
19. Audio/visual recording	Audio-recording of all interviews
20. Field notes	Yes
21. Duration	Approximately 1 hour
22. Data saturation	Yes
23. Transcripts returned	3 interviewees wanted to receive the transcripts, which they did.
DOMAIN 3: Analysis and findings	
Data analysis	
24. Number of data coders	2
25. Description of the coding tree	Available upon request
26. Derivation of themes	Derived from the data
27. Software	Atlas-ti 7.1.15
28. Participant checking	Two participants provided feedback upon request.
Reporting	
29. Quotations presented	Yes
30. Data and findings consistent	Yes
31. Clarity of major themes	Yes
32. Clarity of minor themes	Yes

Note: Consolidated Criteria for Reporting Qualitative Studies (COREQ): A 32-item checklist[32]

CHAPTER 4

Collaborative goal setting with elderly patients with chronic disease or multimorbidity: a systematic review

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Marjan Faber

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Abstract

Background: It is challenging to use shared decision-making with patients who have a chronic health condition or, especially, multimorbidity. A patient goal-oriented approach can thus be beneficial. This study aims to identify and evaluate studies on the effects of interventions that support collaborative goal setting or health priority setting compared to usual care for elderly people with a chronic health condition or multimorbidity.

Methods: This systematic review was based on EPOC, PRISMA and MOOSE guidelines. Pubmed, PsychInfo, CINAHL, Web of Science, Embase and the Cochrane Central Register of Controlled Trials were searched systematically. The following eligibility criteria were applied: 1. Randomised (cluster) controlled trials, non-randomised controlled trials, controlled before-after studies, interrupted time series or repeated measures study design; 2. Single intervention directed specifically at collaborative goal setting or health priority setting or a multifactorial intervention including these elements; 3. Study population of patients with multimorbidity or at least one chronic disease (mean age ± standard deviation (SD) incl. age 65). 4. Studies reporting on outcome measures reducible to outcomes for collaborative goal setting or health priority setting.

Results: A narrative analysis was performed. Eight articles describing five unique interventions, including four cluster randomised controlled trials and one randomised controlled trial, were identified. Four intervention studies, representing 904, 183, 387 and 1921 patients respectively, were multifactorial and showed statistically significant effects on the application of goal setting (Patient Assessment of Chronic Illness Care (PACIC) goal setting subscale), the number of advance directives or the inclusion of goals in care plans. Explicit attention for goal setting or priority setting by a professional was a common element in these multifactorial interventions. One study, which implemented a single-factor intervention on 322 patients, did not have significant effects on doctor-patient agreement. All the studies had methodological concerns in varying degrees.

Conclusions: Collaborative goal setting and/or priority setting can probably best be integrated in complex care interventions. Further research should determine the mix of essential elements in a multifactorial intervention to provide recommendations for daily practice. In addition, the necessity of methodological innovation and the application of mixed evaluation models must be highlighted to deal with the complexity of goal setting and/or priority setting intervention studies.

Background

The number of morbidities and especially the proportion of patients suffering from multimorbidity increase with age. A cross-sectional study of one-third of the Scottish population found that half of the population suffered from at least one morbidity by the age of 50 and most people were multimorbid by the age of 65 [1]. Chronic health conditions and multimorbidity (i.e. the coexistence of two or more chronic morbidities) are challenges in the decision-making process between practitioners and patients. A patient goal-oriented approach to health care could be beneficial and contribute to a patient's wellbeing and quality of life [1-4].

However, goal setting and/or priority setting with elderly patients within the framework of a chronic health condition or multimorbidity is complex. Disease-specific guidelines are often not applicable to elderly patients with multiple conditions [5]. Health-related goals can arise from a variety of dimensions [6 7]. Moreover, care-related goals for community-dwelling frail older adults differ between individuals and often also cover wellbeing, just as much as health and functioning [8]. These different types of goals, which are often implicit, can conflict [9]. In addition, a patient and a physician can also have competing priorities [5 10]. Therefore, practitioners need approaches for revealing and reconciling their own and their patients' priorities. However, the availability and effects of approaches for reconciling clinicians' own and their patients' priorities and setting goals are not yet clear [5]. Collaborative goal setting, defined as 'a process by which health care professionals and patients agree on a health-related goal' [11], could be useful for personalising care and adapting it to a patient's goals, values and resources. Systematic reviews have been conducted on (collaborative) goal setting in varying rehabilitation settings [12-15]. To our knowledge, however, there has not yet been a systematic review of the effects of interventions supporting collaborative goal setting and/or priority setting for the population of older patients with a chronic health condition or multimorbidity independent of setting. Therefore, we aim to systematically review the availability and effects of interventions supporting collaborative goal setting and/or priority setting compared to the usual care for elderly people with a chronic health condition or multimorbidity.

Methods

This review was developed and conducted based on the Effective Practice and Organization of Care Cochrane collaboration guidelines (EPOC), Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) and Meta-analysis Of Observational Studies in Epidemiology (MOOSE) guidelines [16-18] resp.. The PRISMA checklist is included in Additional file 4.1. Our review protocol is available upon request.

Concept of collaborative goal setting

The concept of collaborative goal setting is still under development. For our review, we defined 'collaborative' as 'an exchange of knowledge and information and/or cooperation between the professional(s) and the patient' or as 'a situation in which a patient is coached or supported by a professional'. Since the concept of collaborative goal setting within the framework of decision-making is still being developed, we also included studies that used similar terminology, like 'mutual' or 'shared'. Moreover, as the distinction between 'goal setting' and 'health priority setting' is not always clear, both concepts were included in our search for relevant studies.

Since the concepts of collaborative goal setting and/or health priority setting in this context are under development, there are no established outcome measures. Therefore, we could not define all the relevant outcome measures up front. To avoid missing relevant studies, we included studies that reported on outcome measures reducible to collaborative goal setting and/or health priority setting. We did not report on the remaining outcomes of the included studies.

Search strategy

We performed a systematic search in Pubmed, PsychInfo, CINAHL, Web of Science, Embase and the Cochrane Central Register of Controlled Trials, limited to publications in English and Dutch and including only the period from January 1990 to November 2015. The Pubmed search strategy, including search terms, is reported in Additional file 4.2. The study protocols obtained in the search were checked for published results. The reference lists in the reviews included in the search, as well as the reference lists of all included articles, were checked for possible missing studies.

Study selection

Two researchers (NV and MH) screened titles and abstracts independently. The same researchers also selected the full texts independently. The following eligibility criteria were applied: randomised controlled trials (RCTs), non-randomised controlled trials (NRCTs), controlled before-after (CBA) studies, interrupted time series (ITS) and repeated measures studies. The population criterion was patients with multimorbidity or at least one chronic disease (mean age ± standard deviation incl. age 65). Both single and multifactorial interventions supporting collaborative goal setting or health priority setting were included. Included studies had to report on outcome measures reducible to collaborative goal setting and /or health priority setting.

Data extraction and quality assessment

One investigator (MH) extracted study characteristics and outcomes from the included

studies. These were checked by another investigator (NV). The data extraction form was based on EPOC's 'Data collection form: Intervention review – RCT and non-RCTs' [16]. Risk of bias was assessed by two researchers (NV and MF) independently and then compared to evaluate the quality of the individual articles, according to the criteria for EPOC reviews [19].

Data synthesis and analysis

Conducting a meta-analysis was not feasible because of the multifactorial character and variability of interventions. The results of the included studies were narratively analysed and interpreted.

Results

A flow chart of the selection procedure is included in Figure 4.1. The initial search identified 3589 citations. Based on the full-text assessment of 120 articles, five articles were included.

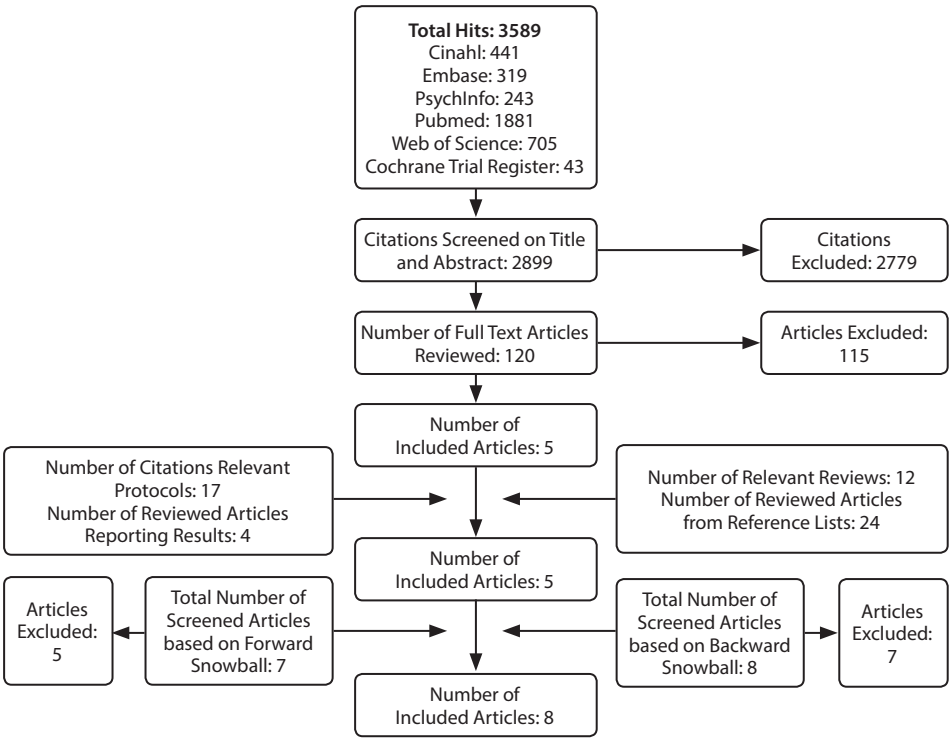

Figure 4.1 **Flow diagram of the selection procedure**

This flow diagram is based on the PRISMA Flow Diagram 2009. It provides a summary of the different selection steps and indicates source, type of selection and numbers of inclusions and exclusions.

The full-text assessment of the related articles about 17 study protocols did not result in any extra inclusions. Checking the references of 12 relevant reviews in the initial database search with additional full-text assessment of 24 articles did not result in any additional inclusions.
Three articles were included based on the backward and forward reference checking of all included articles. The reasons to exclude full-text articles in relation to our eligibility criteria were study design (36), intervention (27), provider (13), multimorbidity or chronic condition (2), age (7), outcome (49) or a combination of criteria (45). Eventually, eight articles were included in this review.

Risk of bias

All articles showed methodological concerns in varying degrees. The only risk of bias criterion that all studies scored 'low risk' on was allocation concealment. Four articles reported differences in the baseline characteristics of the intervention and control population, and two articles scored 'unclear risk' on this criterion. Five articles scored 'unclear risk' on protection against contamination. All the articles included 'other risks of bias' in the evaluation in the discussion; these risks (included in Additional file 4.3) were assessed as 'unclear' since their effects are unknown. All risks are summarised in Figure 4.2. The elaborate risk assessment results that substantiate Figure 4.2 are available upon request.

Interventions in support of collaborative goal setting or health priority setting

The eight articles included in this review reported on five unique interventions. Based on these interventions, a distinction could be made between two articles reporting on the same underlying study on a single intervention concerning health priority setting, the PrefCheck [20 21], and four multifactorial interventions in which goal setting and/or priority setting are part of a broader intervention. Three of the four multifactorial interventions described the same underlying study on the effects of Guided Care (GC) [22-24]. All the remaining articles dealt with distinct interventions, namely Helping Older People Experience Success (HOPES), the Collaborative Care Model and Integrated Systematic Care for Older People (ISCOPE) ([25-27] resp.).
Details of the interventions are summarised in Table 4.1. The PrefCheck (i.e. preferences in treatment planning for older patients) is the only included study that specifically focuses on shared priority setting between general practitioner (GP) and patient. In the PrefCheck intervention, a trained GP holds a consultation based on a specially developed guide, the PrefCheck. After the patient rates the importance of each existing health problem, the patient and GP exchange and document health and treatment priorities [20 21].

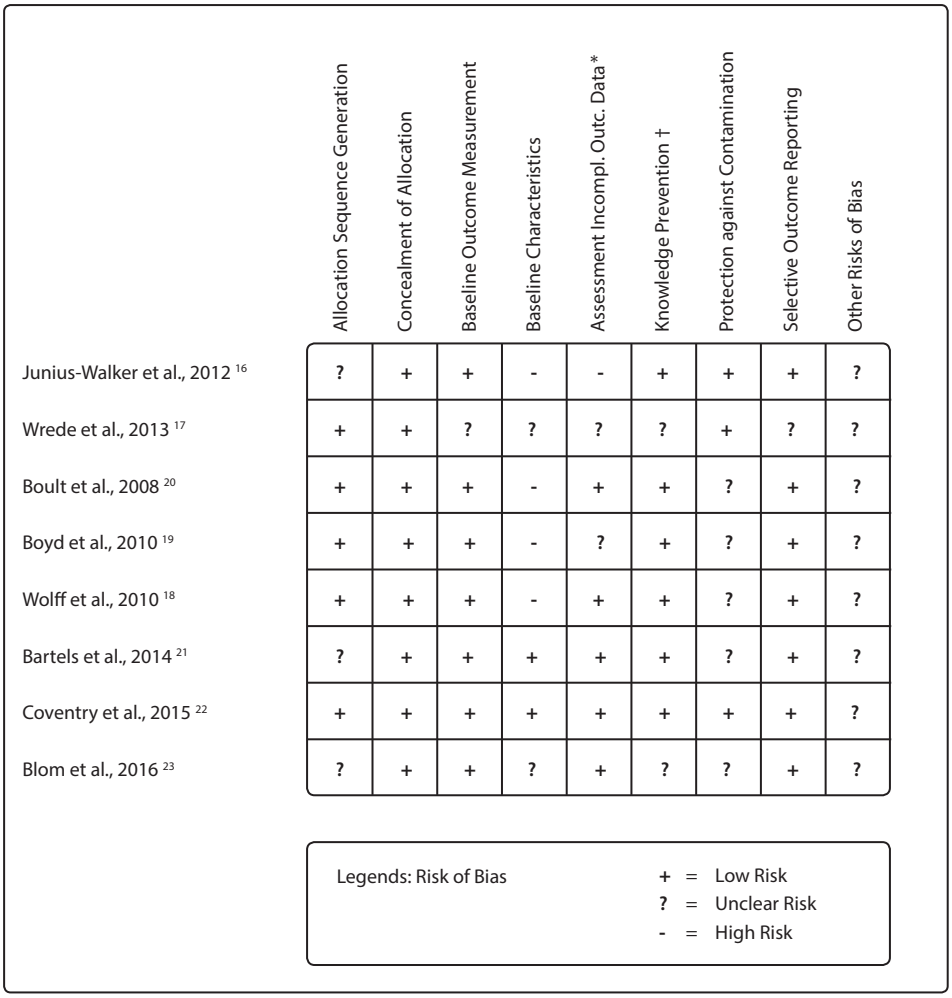

Figure 4.2 **Risk of bias of included studies**

*Assessment of Incomplete Outcome Data
†Knowledge Prevention of Allocated Interventions

This figure summarises the risk of bias assessment of the articles included in this review. Risk assessment was based on criteria for EPOC reviews [16]. Allocation was adequately concealed (low risk) if the unit of allocation was by institution, team or professional, and allocation was performed on all units at the start of the study or if the unit of allocation was by patient or episode of care and a centralised randomisation scheme was used. The allocation sequence is adequately generated (low risk) if a random component in the sequence generation process is described. If there is no evidence of selective outcome reporting, this criterion is assessed as low risk. Baseline outcome measurements should show no important differences across study groups prior to the intervention (low risk). Baseline characteristics are assessed as low risk if reported and similar. Missing outcome measures should be unlikely to bias the results (low risk). Knowledge of the allocated intervention by assessors of primary outcome variables should be adequately prevented or the outcomes should be objective (low risk). The study was adequately protected against contamination if allocation was by community, institution or practice, and it is unlikely that the control group received the intervention. The ninth criterion is 'other risks of bias'.

Table 4.1 **Interventions in individual studies**

Study	Intervention
Junius-Walker et al., 2012 [20]	**Intervention-tool:** PrefCheck The guide consists of the following: (1) Disclosure of the patient's rating of the importance of each health problem in tabular form (2) A three-step guide to the exchange of health and treatment priorities in a patient-centred manner (3) A sheet on which to document priority health problems **Intervention:** 30-minute GP training session in preparation for the priority setting consultations (use of an individual patient-related PrefCheck guide) by a research worker. A computer-aided geriatric assessment by a nurse after patient recruitment. Independent problem importance rating by GPs and patients, followed by a consultation using the PrefCheck. After 14 days, the second round of independent problem importance ratings, followed by a consultation using the PrefCheck. **Nature of desired change:** To improve shared health priority setting between GP and patient. **Timing:** One 30-minute training session. Proximity to clinical decision-making is unclear. PrefCheck was given to the GP immediately before the consultation. 14-days follow-up period. **Comparison:** Standard practice control group (consultation using the patient's problem list without importance ratings and PrefCheck).
Wrede et al., 2013 [21]	**Intervention:** Same as Junius-Walker et al., 2012 **Nature of desired change:** To improve shared health priority setting between GP and patient. **Timing:** 30-minute GP training session in preparation for the priority setting consultations (use of an individual patient-related PrefCheck guide) by a research worker. A computer-aided geriatric assessment by a nurse, after patient recruitment. Independent problem importance rating by GPs and patients, followed by a consultation using the PrefCheck. Research on the first consultation. Follow-up consultations were not evaluated. **Comparison:** Standard practice control group (consultation using the patient's problem list without importance ratings).
Boult et al., 2008 [24]	**Intervention:** Guided Care [28] A registered nurse completes an education programme and then uses a customised electronic health record (EHR) in working with 2 to 5 primary care physicians (PCP) to meet the complex needs of 50-60 older patients with multimorbidity. This Guided Care Nurse (GCN) has eight clinical activities: 1) Assessment: An initial assessment of the patient's medical, functional, cognitive, affective, psychosocial, nutritional and environmental status during a visit at the patient's home. The patient is asked to identify his or her highest priorities for optimising health and quality of life. 2) Planning: The EHR merges assessment data with evidence-based best practice recommendations to create a preliminary Care Guide. This preliminary Care Guide is adapted to reflect this individual patient by: 1. the GCN and the PCP, and 2. the GCN and the patient and caregiver. The final Care Guide summarises the patient's status and plans to all professionals involved and is regularly updated by the GCN. A patient-friendly version (i.e. a lay version), called My Action Plan, is available in the patient's home. 3) Chronic Disease Self-Management (CDSM): The patient's self-efficacy in managing chronic conditions is promoted by referring him or her to a six-session CDSM course.

Study	Intervention
	4) Monitoring: Monthly monitoring by telephone with reminders from the EHR to detect and address emerging problems. These problems are discussed with the PCP and appropriate action is taken. 5) Coaching: In conjunction with the monthly calls, the GCN uses motivational interviewing to reinforce the patient's adherence to the Action Plan. 6) The GCN coordinates transitions between sites and care providers. 7) Educating and supporting caregivers. The GCN offers individual and group assistance to caregivers, consisting of initial assessment, a self-management course for caregivers, monthly support group meetings and ad hoc telephone consultations. 8) The GCN facilitates access to community resources. **Nature of desired change:** Initiation of the Guided Care Model to improve several aspects of health care quality for elderly patients with multimorbidity. **Timing:** Intervention duration 18 months, this article reports on results after 6 and 12 months. **Comparison:** Standard practice control group (usual care instead of guided care).
Boyd et al., 2010 [23]	**Intervention:** Guided Care **Nature of desired change:** Initiation of the Guided Care Model to improve several aspects of health care quality for elderly patients with multimorbidity. **Timing:** Intervention reports on 18 months. **Comparison:** Standard practice control group (usual care instead of guided care).
Wolff et al., 2010 [22]	**Intervention:** Guided Care Program for Family and Friends (GCPFF) The GCN: a) Makes an initial one-to-one assessment of the patient's primary caregiver. b) Educates the caregiver and refers him or her to community resources. c) Offers ongoing 'coaching' to the caregiver. d) Facilitates six 90-minute caregiver workshops based on the chronic disease self-management philosophy and approach. e) Facilitates one-hour-long unstructured monthly support group meetings. **Nature of desired change:** Initiation of the Guided Care Model to improve several aspects of health care quality for elderly patients with multimorbidity from the patient's and caregiver's perspectives. Improvement of caregiver depression, strain and productivity and their perceptions of the quality of patient care. **Timing:** Intervention reports on 18 months. **Comparison:** Standard practice control group (usual care instead of guided care).

Study	Intervention
Bartels et al., 2014 [25]	**Intervention:** Helping Older People Experience Success (HOPES) Combination of community living skills, social skills and healthy-living skills training with integrated preventive care coordinated by a nurse. The intervention contains a psychosocial element, facilitated by rehabilitation specialists; it consists of weekly skills training in group sessions over one year, followed by monthly booster sessions. In addition, two monthly community trips were organised to practise skills. The preventive element, HOPES Health Management, was facilitated by a nurse and consisted of monthly meetings to evaluate health care needs. Collaborative goal setting is part of the health management component. Another step in the health management component is the completion of advance directives. **Nature of desired change:** Improvement of independent functioning and community tenure. **Timing:** 3 years: 1 year intensive phase, 1 year maintenance phase and 1 year follow-up. **Comparison:** Routine mental health services consisted of pharmacotherapy, case management or outreach by non-nurse clinicians, individual therapy, and access to rehabilitation services, such as groups and psycho education. Both intervention and control groups received these services.
Coventry et al., 2015 [26]	**Intervention:** Collaborative Care Model Eight psychological therapy sessions delivered by case managers who are 'psychological well-being practitioners'. In the first treatment session, the psychological well-being practitioner uses a structured patient-centred interview to gather information and then introduces the patient to the standardised treatment manual and workbook to help develop a main problem statement and personalised goals. Two 10-minute collaborative meetings (by telephone or in person) between the patient and the psychological well-being practitioner and a nurse from the patient's general practice. Psychological well-being practitioners also work collaboratively with the patient and the practice nurse to monitor medication use. Use of established stepped care protocols. Psychological well-being practitioners received five days of training about the COINCIDE collaborative care model. Practice nurses followed a half-day workshop. Psychological well-being practitioners attended a weekly supervision session. **Nature of desired change:** Improvement of care access and quality. **Timing:** Eight brief face-to-face psychological therapy sessions (i.e. 30-45 minutes) within 3 months. Two collaborative meetings after sessions 2 and 8. Reports on results measured after 4 months. **Comparison:** Care as usual delivered by the general practitioner.

Study	Intervention
Blom et al., 2016 [27]	**Intervention:** The Integrated Systematic Care for Older PEople The GPs and nurses carrying out the intervention practices were trained in the delivery of proactive integrated care (e.g. in designing, conducting and adjusting a care plan). The GP or the practice nurse (under the supervision of the GP) created an integrated care, action and evaluation plan for participants with complex problems. Other care professionals were involved where needed (multidisciplinary consultation). The participant's wishes and expectations about goals to be achieved were explored together with the informal caregiver(s). These priorities and goals were used as a starting point for making a care plan. **Nature of desired change:** The development of a care plan focusing on functioning for people with complex problems (i.e. a combination of somatic, functional, mental and social health problems). **Timing:** Two 3-hour GP/practice nurse training sessions. Care plans for the first 10 patients per participating GP were made over a two- to three-month period. Follow-up period of 1 year. **Comparison:** Usual care. Participants receiving usual care were not included in the final analysis.

Note: GP = General Practitioner; EHR = Electronic Health Record; PCP = Primary Care Practice; GCN = Guided Care Nurse; CDSM = Chronic Disease Self-Management; COINCIDE = The Collaborative Interventions for Circulation and Depression
Underlined: Goal setting or priority-setting element

Although not designed as an intervention with a single focus on goal setting or health priority setting, the included multifactorial interventions show important similarities. In all these multifactorial interventions, there is an explicit focus on goal setting or priority setting, and goals or priorities are specifically determined. An important similarity is that they all were delivered primarily by a nurse or allied health professional (except for the ISCOPE intervention, which was provided by a GP or a nurse under GP supervision). Secondly, caregiver involvement was a common component in GC [22-24] and the ISCOPE intervention [27]. One of the GC studies focused on caregivers in particular [22]. Furthermore, training the professional providing the intervention was explicitly mentioned in GC [22-24], ISCOPE [27] and the Collaborative Care Model [26]. In addition, an educational programme for the patient involved was a common component in GC [22-24], the HOPES intervention [25] and the Collaborative Care Model [26]. Finally, explicit care planning was a common element in all the multifactorial interventions. Although there were common components as analysed above, these multifactorial interventions also showed considerable differences due to variability in the underlying model and study focus.

Study and participant characteristics

One study used a randomised controlled trial design [25] and the remaining four were cluster randomised trials. In all the included studies, the intervention group was compared to the usual care or to standard practice. The number of study participants ranged from 42 to 1921 patients. One study focused on patients with a chronic disease, namely a serious mental illness [25]. One study recruited patients with diabetes and/or coronary heart disease who had also suffered from depressive symptoms for at least two weeks [26]. The remaining studies used a geriatric assessment [20 21 27] or Hierarchical Condition Category (HCC) [22-24] scores to determine multimorbidity. Although all the included studies satisfied our age criterion, two of them originally did not apply the 'age 65 or older' inclusion criterion for the underlying trial, but focused on broader age categories [25 26]. Most of the studies were conducted in a general practice/primary care practice; one was conducted in a community mental health centre [25]. The studies were carried out in the USA [22-25], UK [26], Germany [20 21] and the Netherlands [27]. The details of study and participant characteristics are summarised in Table 4.2.

Table 4.2 **Study and participants' characteristics**

Study	Study design	Intervention	Participants		Outcomes
Junius-Walker et al., 2012 [20]	Cluster RCT	PrefCheck	Country	Germany	Doctor-patient agreement about the importance ratings of individual health problems Determination of priorities Rates of priority problem treatment planning
			Setting	GP/PCP	
			Number	322 participants	
			Condition	Multimorbidity*	
			Study age criterion	≥ 70 years of age	
			Study age	Intervention group: M=76.9, no range reported	
				Control group: M=77.5, no range reported	
Wrede et al., 2013 [21]	Cluster RCT	PrefCheck	Country	Germany	Importance ratings discussed Prioritization at consultation level, health problems level and nature of the health problem level
			Setting	GP/PCP	
			Number	42 consultations	
			Condition	Multimorbidity*	
			Study age criterion	≥ 70 years of age	
			Study age	Intervention: M=77.0, IQR=71.3-81.8	
				Control group: M=78.0, IQR=75.0-81.0	
Boult et al., 2008 [24]	Cluster RCT	Guided Care	Country	USA	PACIC‡ goal setting subscale
			Setting	GP/PCP	
			Number	904 participants	
			Condition	Multimorbidity†	
			Study age criterion	≥ 65 years of age	
			Study age	Intervention M=77.2, range 66-106	
				Control group M=78.1, range 66-96	
Boyd et al., 2010 [23]	Cluster RCT	Guided Care	Country	USA	PACIC‡ goal setting subscale
			Setting	GP/PCP	
			Number	904 participants	
			Condition	Multimorbidity†	

Study	Study design	Intervention	Participants		Outcomes
			Study age criterion	≥ 65 years of age	
			Study age	Intervention M=77.2, range 66-106	
				Control group M=78.1, range 66-96	
Wolff et al., 2010 [22]	Cluster RCT	Guided Care Program for Family and Friends (GCPFF)	Country	USA	PACIC‡ goal setting subscale. Ratings by caregivers
			Setting	GP/PCP	
			Number	308 caregiver-patient pairs	
			Condition	Multimorbidity†	
			Study age criterion	≥ 65 years of age (patient)	
			Study age	Intervention group (patient): M=78.0, SD=0.6	
				Control group: M=77.9, SD=0.7	
Bartels et al., 2014 [25]	RCT	Helping Older People Experience Success (HOPES)	Country	USA	Rate of completed advance directives
			Setting	Community mental-health agency	
			Number	183 participants	
			Condition	SMI	
			Study age criterion	≥ 50 years of age	
			Study age	Intervention group: M=60.3, SD=8.0	
				Control group: M=60.1, SD=7.1	
Coventry et al., 2015 [26]	Cluster RCT	Collaborative Care Model	Country	United Kingdom	PACIC‡ goal setting subscale
			Setting	GP/PCP	
			Number	387 participants	
			Condition	DM or CHD and depression§	
			Study age criterion	≥ 18 years of age	
			Study age	Intervention group: M=57.9, SD=12.0	
				Control group: M=59.2, SD=11.4	

Study	Study design	Intervention	Participants		Outcomes
Blom et al., 2016 [27]	Cluster RCT	The Integrated Systematic Care for Older PEople (ISCOPE) study	Country	The Netherlands	Median number and percentage of goals in care plans
			Setting	GP/PCP	
			Number	1921 participants	
			Condition	Multimorbidity*	
			Study age criterion	≥ 75 years of age	
			Study age	Intervention - not selected for care plan: M=82.7, median=79.2, IQR=87.1	
				Intervention-selected for care plan: M=82.0, median=78.8, IQR=86.9	
				Control group: M=83.7, median=79.8, IQR=88.0	

Note: ClusterRCT = Cluster Randomised Controlled Trial; GP = General Practice; PCP = Primary Care Practice; M = mean; IQR = interquartile range; USA = United States of America; PACIC = Patient Assessment of Chronic Illness Care; SMI = serious mental illness; SD = standard deviation; DM = Diabetes Mellitus; CHD = Chronic Heart Disease

*multimorbidity based on geriatric assessment

†multimorbidity based on Hierarchical Condition Category (HCC) scores

‡ Patient Assessment of Chronic Illness Care (PACIC) [28]

§Patients with diabetes mellitus and/or coronary heart disease who also had depressive symptoms for at least two weeks

Effects on outcome measures

Two articles on the same trial applying the PrefCheck intervention reported on the rates of determined priorities [20 21]. One article [20] only reported the determination and planning of priorities for the intervention group. Intervention GPs determined priorities together with 70% of patients. Treatment was planned for 84% of the priority problems and 37% of the non-priority problems. The PrefCheck intervention did not lead to an improvement in doctor-patient agreement about the importance of health problems [20].

The second article [21], based on 43 recorded consultations between 28 general practitioners and their patients, examined the effects of the PrefCheck intervention to determine the extent to which shared health priorities were set and facilitated through patient-centred behaviour. Twenty-four consultations were held in the intervention group; the remaining 19 consultations belonged to the control group. General statements about setting priorities were made to clarify the purpose of prioritisation in 27.9% of all consultations (i.e. 12/43). It is not clearly stated whether these are intervention or control consultations. Six consultations held with the control group (n=19) and nine consultations held with the intervention group (n=24) addressed the importance of at least one health problem. No statistical significance of this outcome was reported [21]. At the health problems level (n=216 health problems), an agreement on priority treatment was reached in only seven consultations (i.e. 3.2%). No agreements were made about setting priorities for everyday problems (n=65) [21].

The rate of completed advance directives was considered an outcome measure for determined priorities and goals. The HOPES intervention increased the rate of completed advance directives in the intervention group versus the control group (61% versus 33%, effect size .59) [25].

The number of goals as part of a care plan was also considered a relevant outcome for our review. In the ISCOPE study, 288 participants were randomly selected to receive a care plan in which problems, goals and actions could be integrated. For 15% (n=43) of them, a care plan was not prepared by the GP. In the interventional care plans, the median numbers of problems, goals and actions were the following: 3 (interquartile range (IQR) 2–4), 4 (IQR 2–5) and 3 (IQR 2–5), respectively [27]. We contacted the author to verify whether the numbers for the control group were also available. The author informed us that four patients who were not part of the selected group of 288 participants also received a care plan.

The Patient Assessment of Chronic Illness Care (PACIC) scale collects patient reports on the actions taken and the care received in line with the Chronic Care Model and intends to assess the patient-centred care received, with a focus on collaborative goal setting, problem solving and follow-up as key elements of self-management support [29]. In addition to an aggregate quality measurement, the PACIC scale consists of five subscales, i.e. goal setting, care coordination, decision support, problem solving and patient activation [24]. The

PACIC's 'goal setting' subscale is a relevant outcome measure for our review.
In the evaluation of the effects of the GC model, goal setting was considered to be 'high quality' when it occurred 'most of the time' or 'always' [24]. The studies applying the GC model and the Collaborative Care Model reported on the PACIC scale. In the GC model, the percentage of patients rating goal setting as 'high quality' after receiving care for six months was significantly higher for GC patients than for patients who received the usual care (i.e. 24.6% versus 11.6%, adjusted Odds Ratio (OR) 2.37, $p < .001$) [24]. Although no longer significant at the $p < .05$ level, the percentage of patients rating goal setting as 'high quality' after receiving care for 18 months was still higher for GC patients than for patients who received the usual care (i.e. 23.1% versus 15.3%, adjusted OR 1.53 ($p = .005$) [23].
In the Collaborative Care Model, patients' scores on the goal setting subscale were higher in the collaborative arm than in the 'usual care arm' (mean 2.18 (SD 1.2) versus mean 1.77 (SD 1.0)) with an effect size of 0.37. This indicates that this care model was moderately effective in stimulating goal setting as an element of chronic care [26].
One article focused on the Guided Care Program for Family and Friends (GCPFF) [22] included caregiver reports that assessed the aggregate quality of chronic illness care provided to their care recipients by means of a modified version of the PACIC scale. On the goal setting subscale, quality ratings by caregivers in the GCPFF were significantly higher (mean 3.1 (Standard Error (SE) 0.13) versus mean 2.7 (SE 0.13)), with an effect size (ES) of 0.47 (95% confidence interval (ES) 0.15 to 0.79)).

Discussion

Health care for elderly patients with a chronic health condition or multimorbidity may benefit from a switch from a disease-specific approach to a patient goal-orientation [1-4]. Collaborative goal setting and/or health priority setting are necessary elements in this approach. This systematic review evaluates the effects of interventions supporting collaborative goal setting or health priority setting compared to usual care.
The possible benefits of a patient goal-orientation in care for elderly patients with a chronic disease or multimorbidity are increasingly recognised. However, compelling evidence for its benefits is lacking. Our review process and results made it retrospectively clear that collaborative goal setting or health priority setting constitutes a relevant but 'premature' review topic. The review does, however, make a significant contribution to the further development of patient goal-oriented health care in three areas: the concept of collaborative goal setting, single versus multifactorial interventions, and outcome measures and effects of collaborative goal setting or priority setting.

The concept of collaborative goal setting

The concepts of 'collaborative goal setting' and 'priority setting' in this context are still under development. Moreover, our review illustrates that the distinction between them is not clear. In the evaluation of health priority setting in GC, the PACIC scale is used (i.e. a subscale on patients' evaluation of goal setting). Priority setting can be considered part of goal setting or a separate, though related, concept. Within the framework of theory development as well as in the daily practice of care for elderly patients with multimorbidity, it is important to clearly define 'priority setting' and 'goal setting' and their mutual relation in the future.

An earlier systematic review addressed the evidence of complex interventions related to patient goal-oriented health care, focusing on personalised care planning [30]. Our review differs from that review in two ways that are related to the concepts of 'collaborative goal setting' and 'priority setting'. In Coulter's review, goal setting is an element of personalised care planning, which includes action planning. Attainment of personal goals is a secondary outcome in this review. Only four of the 19 included articles reported on goal achievement. In the research implications, it is advised that future researchers examine the effects of personalised care planning on goal attainment, especially a patient's personal goals as opposed to goals determined by clinicians or researchers. However, the concept and potential benefit of *collaborative* goals for clinical practice are not explicitly discussed in this review. Instead we focus on interventions concerning goal setting or priority setting as a *collaborative* process and aim to evaluate the effects of these collaborative goals and priorities. In addition, our review focuses on interventions supporting goal setting or priority setting without the limitation of a specific concept of care in the search strategy.

Within the framework of theory development as well as in the daily practice of care, it is also important to clearly define 'shared decision-making' and 'goal setting' and their mutual relation. For the time being, this mutual relation is not yet clearly defined. Goal setting is not an explicit element of the integrative definition of shared decision-making put forth by Makoul et al. [31]. Rose et al. [32] focused on shared decision-making *within* goal setting in rehabilitation settings. However, a 'goal talk' could also be viewed as a component of a shared decision-making process [33].

Single versus multifactorial interventions

It follows from our study that single interventions regarding collaborative goal setting and/or priority setting are rare. They are usually components within varying multifactorial interventions. A systematic review of the related topic of the effectiveness on health outcomes of instrumental tools to assess patient treatment priorities and preferences within the framework of multimorbidity concluded that there is a lack of such tools, which is in line with our findings [34].

Considering the effectiveness of multifaceted or multifactorial interventions versus single-component interventions in changing health care professionals' behaviour, an overview of systematic reviews showed that there is no compelling evidence that multifaceted interventions are more effective than single-component interventions [35]. However, the total effect of a multifaceted strategy depends on the effectiveness of its components and the interaction between them [36]. Based on the single-component character of a single intervention study only, it is too early to conclude that single interventions on health priority setting or collaborative goal setting would generally be ineffective. Nevertheless, in daily practice it is difficult to separate goal setting or priority setting from other care elements. Multifactorial interventions with an optimal mix of components seem to be the most promising in this phase of developing interventions that support goal setting or priority setting.

Our analysis of the multifactorial interventions found several common elements. Explicit care for goal setting or priority setting by a specific professional was one. However, there was variation in which person within the health care team provided the intervention. This could be a GP, a nurse, a GP and/or a practice nurse or a psychological wellbeing practitioner. This person could be part of the regular health care team or be introduced to the team based on the intervention. In addition, involvement of caregivers, training of intervention professionals, patient education and care planning were common elements in several or all interventions. However, these elements also showed considerable variability. Training of intervention professionals varied in time. The intervention duration and follow-up were also variable. Health priority setting and /or goal setting could be done in a separate consultation, could be the starting point of a broader care programme or be part of a preventive health management component. From this variability in content and use of generally common elements, it becomes clear that it is too early to give general recommendations for clinical practice at this stage, especially since we only found interventions in non-hospital settings. It could be useful to consider these aspects in further research and in the development of interventions including collaborative goal setting and/or priority setting.

Outcome measures and effects of collaborative goal setting or priority setting

Despite the developmental phase of these interventions, we identified eight articles (i.e. seven cluster randomised and one randomised control trials) that described five unique interventions and relevant outcome measures that are reducible to collaborative goal setting and/or priority setting. The four multifactorial interventions had significant effects on the application of goal setting [22-24 26], the number of advance directives [25] or led to the inclusion of problems, goals and actions in care plans [27]. The single intervention [20 21] did not have a significant effect on doctor-patient agreement.

Limitations

Identifying relevant articles in this broad topic area was challenging. Concepts and terminology are not always evident, and interventions are still under development. Most articles on integrated interventions do not focus on collaborative goal setting or priority setting, which may have led to our missing articles. We tried to prevent this by using a broad search terminology and a lengthy time period and by seeking additional information on articles and applying an extensive snowball procedure. Due to the restriction to publications in English and Dutch, potentially eligible articles in other languages may also have been excluded.

Due to a lack of established outcome measures, the relevant outcome measures could not be defined up front. To avoid missing relevant studies, we included studies that reported on outcome measures that are directly reducible to collaborative goal setting and/or health priority setting.

All the articles showed risks of bias in various degrees. This may be due to the behavioural character of the interventions and outcomes. The same limitation was described in systematic reviews on interventions in personalised care planning and patient-centred care, which conceptually overlap with patient goal-oriented health care [30 37].

Six of our reviewed articles dealt with four unique multifactorial interventions. Collaborative goal setting or priority setting constituted only one element of these interventions and their outcomes. It is impossible to draw clear conclusions on the effects of collaborative goal setting or priority setting within such a complex model, as other parts of the intervention may establish possible confounding effects. The included studies also report on different populations (as shown in Table 4.2), leading to difficulties when generalising results.

Conclusions

To improve health care for elderly patients with chronic (multi)morbidity, it is inevitable to switch from a disease-specific approach to a focus on patient goals, including collaborative goal setting. A specific focus on collaborative goal setting and/or priority setting was mostly found in a multifactorial intervention, which seems to improve the application of goal setting and the numbers of agreed upon goals and advance directives. Although explicit care for goal setting or priority setting by a specific professional was a common element in the reviewed multifactorial interventions, it remains unclear which mix of key components makes the difference. Further research should determine the mix of essential elements within a multifactorial intervention to provide recommendations for daily practice. Conceptual clarity on collaborative goal setting and priority setting is a prerequisite for this. In addition, the evaluation of complex goal setting intervention studies is challenging and demands methodological innovation.

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Additional files

Additional file 4.1 **PRISMA 2009 checklist**

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	69
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	70
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	71
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	71
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	71
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	72
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	72
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Additional File 4.2
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	72-73
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	72-73
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	72
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	72-73
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	Not applicable

Section/topic	#	Checklist item	Reported on page #
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency for each meta-analysis.	Not applicable
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	74
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	Not applicable
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	73-74 Fig 4.1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	74-83; Table 4.1; 4.2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	74; Fig 4.2
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	84-85 Table 4.2
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Not applicable
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	Not applicable
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	Not applicable
DISCUSSION			
Summary of evidence	24	Summarise the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., health care providers, users, and policy makers).	85-87
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	88
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	88
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Thesis funding statement

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

Additional file 4.2 **Pubmed search strategy**

Date search: 02-12-2015
Hits: 1881

1	aged[mesh]
2	older[tiab]
3	elderly[tiab]
4	geriatr*[tiab]
5	1 OR 2 OR 3 OR 4
6	"Chronic Disease"[Mesh]
7	chronic disease*[tiab]
8	6 OR 7
9	"Comorbidity"[Mesh]
10	multimorbid*[tiab]
11	multimorbid*[tiab]
12	multi morbid*[tiab]
13	comorbid*[tiab]
14	co-morbid*[tiab]
15	co morbid*[tiab]
16	9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15
17	8 OR 16
18	"Patient-Centered Care"[Mesh]
19	"Patient Care Planning"[Mesh]
20	18 OR 19
21	"Decision Making"[Mesh])
22	20 AND 21
23	shared[tiab]
24	decision making[tiab]
25	decision-making[tiab]
26	decisionmaking[tiab]
27	goal[tiab]
28	goals[tiab]
29	24 OR 25 OR 26 OR 27 OR 28
30	23 AND 29
31	22 OR 30
32	goal setting[tiab]
33	mutual goal*[tiab]
34	patient engagement[tiab]
35	collaborative partner*[tiab]
36	informing[tiab]
37	listening[tiab]
38	reasoning[tiab]
39	negotiating[tiab]

40 patient centered[tiab]
41 patient-caregiver relationship[tiab]
42 patient care planning[tiab]
43 advance care planning[tiab]
44 care plan[tiab]
45 care plans[tiab]
46 care-plan[tiab]
47 care-plans[tiab]
48 goal attainment scaling[tiab]
49 goal oriented[tiab]
50 optimal care[tiab]
51 goal-oriented approach[tiab]
52 goal-orientation[tiab]
53 goal orientation[tiab]
54 health priorities[tiab]
55 holistic approach[tiab]
56 priority setting process[tiab]
57 self management[tiab]
58 self-management[tiab]
59 collaborative goal-setting[tiab]
60 collaborative goal setting[tiab]
61 collaborative goal[tiab]
62 collaborative goals[tiab]
63 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53 OR 54 OR 55 OR 56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62
64 English [Language]
65 Dutch[Language]
66 64 OR 65
67 ("1990/01/01"[Date - Publication] : "3000"[Date - Publication])
68 17 AND 63
69 68 AND 66
70 69 AND 67
71 5 AND 70

Additional file 4.3 **Other risks of bias**

Author	Other risks of bias as reported by the authors
Junius-Walker et al., 2012 [20]	Shortness of consultation time and doctors' training Re-evaluation of on average 12 problems per patient could be difficult for participating practitioners to achieve
Wrede et al., 2013 [21]	Small numbers of participants and audio recordings Lack of conceptual clarity around terms like prioritisation and patient-centredness Shortness of consultation time and doctors' training
Boult et al., 2008 [24]	Small number of nurses (7) Reliance on self-reported data Limited consent rate Geographic scope (urban mid-Atlantic states in the USA)
Boyd et al., 2010 [23]	Only 38% of high-risk patients consented to participate Less complete entry of diagnoses by practices Proxies' ratings of the PACIC were accepted Assumption of a common treatment effect across teams within each practice
Wolff et al., 2010 [22]	Multifaceted nature of the intervention Heterogeneity in patient and caregiver characteristics Uncertainty about the extent to which nurses implemented the model Power of the study is based on its ability to detect changes in patient rather than caregiver outcomes Relatively small number of caregivers Inability to disentangle which components of the intervention did or did not work or were most salient to patients and caregivers Unclear which outcomes are most salient to caregivers
Bartels et al., 2014 [25]	Study sample was predominantly white Attribution of study outcomes to intervention components Needed more targeted disease management and longer follow-up period to demonstrate improved health outcomes
Coventry et al., 2015 [26]	Short follow-up period Self-reported data on the use of antidepressants General practitioners in both arms were notified that participants met criteria for depression No collection of objective measures of physical functioning
Blom et al., 2016 [27]	Non-responders were slightly more vulnerable No data on fidelity to the care plan No repeated assessments over a longer period

Note: GP = General Practitioner; HCC = Hierarchical Condition Category; PACIC = Patient Assessment of Chronic Illness Care

CHAPTER 5

Assessment of goals and priorities in patients with a chronic condition: A secondary quantitative analysis of determinants across 11 countries

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Gert Westert
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Abstract

Objective: To assess the impact of patient characteristics, patient-professional engagement, communication and context on the probability that health care professionals will discuss goals or priorities with older patients.

Design: Secondary analysis of cross-sectional data from the 2014 Commonwealth Fund International Health Policy Survey of Older Adults.

Setting: 11 western countries.

Subjects: Community-dwelling adults, aged 55 or older.

Main outcome measure: Assessment of goals and priorities.

Results: The final sample size consisted of 17,222 respondents, 54% of whom reported an assessment of their goals and priorities (AGP) by health care professionals. In logistic regression model 1, used to analyse the entire population, the determinants found to have moderate to large effects on the likelihood of AGP were information exchange on stress, diet or exercise, or both. Country (living in Sweden) and continuity of care (no regular professional or organisation) had moderate to large negative effects on the likelihood of AGP. In model 2, which focussed on respondents who experienced continuity of care, country and information exchange on stress and lifestyle were the main determinants of AGP, with comparable odds ratios to model 1. Furthermore, a professional asking questions also increased the likelihood of AGP.

Conclusion: Continuity of care and information exchange are associated with a higher probability of AGP, while people living in Sweden are less likely to experience these assessments. Further study is required to determine whether increasing information exchange and professionals asking more questions may improve goal setting with older patients.

Introduction

Multimorbidity, the coexistence of two or more chronic morbidities, is highly prevalent among older people. A cross-sectional study of about one-third of the Scottish population concluded that half of them suffered from at least one morbidity by the age of 50 and most were multimorbid by the age of 65 [1]. The 2014 Commonwealth Fund International Health Policy Survey of Older Adults, which surveyed adults aged 55 and above in 11 countries, confirmed these results. For respondents aged 65 or older, the percentage with one chronic disease varied from 63% (New Zealand) to 87% (USA), and the percentage with two or more diseases varied from 33% (UK) to 68% (USA) [2].

Globally, multimorbidity rates are rising due to urbanisation, industrialisation and population aging, increasing the demands on the health care work force and resources [3]. In daily practice, the presence of chronic multimorbidity presents a challenge for the decision-making processes between practitioners and patients; applying disease-specific guidelines to patients with multiple conditions is difficult, and this is compounded by the fact that the patients' health-related goals arise from a variety of dimensions [4-7]. An assessment of patient goals and preferences could be helpful for overcoming this challenge [5 8-10]. For individual patients, a goal-oriented approach to health care can contribute to their well-being and quality of life, by changing the focus from a disease-specific orientation to the patient's individual health goals. For societies, this approach and change in focus could also contribute to the long-term quality, accessibility and affordability of the health care system [1 3 5 8-11].

The 2014 Commonwealth Fund survey found that, for adults aged 65 or older who have a chronic condition, the rate of patients sharing their goals with a professional varied from 23% (Sweden) to 59% (UK), with nine of the 11 countries having rates lower than 50% [2]. Sharing goals is clearly not yet a common care practice; therefore, the aim of this secondary analysis of the 2014 Commonwealth Fund data is to assess which factors determine whether health care professionals engage in an assessment of the goals or priorities associated with medical care in older patients with one or more chronic diseases.

Material and methods

Study design, setting and subjects

This empirical analysis was designed and conducted based on the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) Statement [12 13]. The Commonwealth Fund's 2014 International Health Policy Survey of Older Adults had a cross-sectional design and surveyed community-living adults aged 55 or older. This computer-assisted telephone

survey was conducted between March and May 2014 in 11 countries: Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the UK and the USA. The questionnaire was developed, translated, adapted to local health system contexts, and pre-tested by The Commonwealth Fund and SSRS, a market and survey research firm, in co-operation with researchers from the participating countries [2 14].

Telephone surveys were conducted among nationally representative samples of adults aged 55 or older, based on a random-digit-dialling method. Sample generation was performed by Sample Solutions Europe (SSE) (Australia, France, the Netherlands, New Zealand and the UK); SM research (Canada); GESIS, Leibniz-Institut für Sozialwissenschaften (Germany); Norstat (Norway); PAR Konsument registry (Sweden); the Swiss Federal Statistical Office (Switzerland) and SSRS (USA). Both mobile phone and landline numbers were used, except for Canada where only landline phone numbers were used. Telephone numbers were dialled on average nine times in the case of non-response. Prior to conducting the interviews, interviewers received written material on the interviews and were formally trained. Survey topics were: access to care, chronic conditions and care co-ordination, patient engagement, social care needs and end-of-life care planning. On average, interviews lasted 20 minutes [2 14].

The response rates varied from 16% to 60% across the countries (Additional file 5.1) [2], and those with a response rate of less than 20% were dropped from the analysis.

The respondents assessed whether they had one or more chronic conditions by answering whether a doctor had ever told them they had any of the medical conditions on a pre-specified list [14]. The surveys for two countries had additional possible chronic diseases: stroke for France and dementia for Switzerland. Because questions about these additional diseases were limited to those two countries, they were not included in the analyses.

Outcome

Having one or more chronic conditions was a prerequisite for answering the outcome question. The outcome variable 'assessment of goals and priorities' (AGP) had two categories: 'yes' and 'no.' It was based on the following survey question: '*During the past year, when you received care, has any health care professional you see for your (diabetes OR high blood pressure OR heart disease OR chronic lung problems OR depression, anxiety, or another mental health problem OR cancer OR joint pain or arthritis) discussed with you your main goals or priorities in caring for this condition?*' In the context of this question, 'OR' means having one or more of these chronic conditions and seeing a health care professional for any of them.

Possible determinants

We clustered three groups of questionnaire-based variables as possible determinants for AGP. The first group consisted of *Patient Characteristics* and included categorical variables

on age (Age), gender (Gender) and health status; for health status, we created two variables with accompanying groupings: Number_of_Chronic_Conditions and Chronic_Disease_Type. The second group considered *Patient-Professional Engagement and Communication*. Earlier research defined variables (i.e., a professional asking questions, medical staff explaining things in a way that is easy to understand when explanations about care or treatment are required, and a patient's assessment of time spent in a consultation) that capture patient engagement [15]. We created the categorical variables Asking_Questions, Explaining and Time_Spent, respectively. In addition, we created categorical variables about the professional's knowledge of a patient's history (History_Knowledge), and the exchange of information about stress (Information_Exchange_on_Stress) and lifestyle (Lifestyle_Information_Exchange) to build this cluster of factors.

The third group of possible determinants consisted of *Context* variables, including the Country variable (ten categories) and a Continuity of Care (CoC) variable (whether respondents have a regular doctor/health care professional, a regular place for medical care, or neither). Table 5.1 depicts the variables considered to be potential determinants.

Table 5.1 **Univariate analysis of sharing goals and priorities in the Commonwealth Fund International Health Policy Survey of Older Adults**

	Sharing goals and priorities		
	No	**Yes**	**Total**
	n (%)	**n (%)**	**n**
Sample	7903 (45.9)	9319 (54.1)	17222
Population characteristics			
Age (years)			
55–64 (1959–1950)	2457 (41.6)	3447 (58.4)	5904
65–74 (1949–1940)	2903 (45.3)	3506 (54.7)	6409
75+ (1939–1906)	2543 (51.8)	2366 (48.2)	4909
Gender			
Female	4899 (48.1)	5290 (51.9)	10189
Male	3004 (42.7)	4029 (57.3)	7033
Number_of_Chronic_Diseases			
One chronic condition	3631 (50.7)	3525 (49.3)	7156
Two chronic conditions	2520 (45.8)	2979 (54.2)	5499
Three chronic conditions	1752 (38.4)	2815 (61.6)	4567
Chronic_Disease_Type			
Mental disease only	235 (46.8)	267 (53.2)	502
Mental and somatic disease	1099 (43.3)	1438 (56.7)	2537
Somatic disease only	6546 (46.3)	7594 (53.7)	14140
Patient-professional engagement and communication			
Asking_Questions			
Sometimes/Rarely/Never	3096 (60.5)	2020 (39.5)	5116
Always/Often	3976 (36.9)	6787 (63.1)	10763

	Sharing goals and priorities		
	No	Yes	Total
	n (%)	n (%)	n
Explaining			
Sometimes/Rarely/Never	1024 (61.8)	634 (38.2)	1658
Always/Often	6473 (43.2)	8497 (56.8)	14970
History_Knowledge			
Sometimes/Rarely/Never	1248 (61.2)	791 (38.8)	2039
Always/Often	5959 (41.9)	8248 (58.1)	14207
Time_Spent			
Sometimes/Rarely/Never	1427 (60.1)	949 (39.9)	2376
Always/Often	6055 (42.6)	8175 (57.4)	14230
Information_Exchange_on_Stress			
No	6588 (52.3)	6006 (47.7)	12594
Yes	1201 (27.1)	3234 (72.9)	4435
Lifestyle_Information_Exchange			
No exchange	3901 (67.2)	1902 (32.8)	5803
Exchange on diet or exercise	2080 (47.9)	2266 (52.1)	4346
Exchange on diet and exercise	1782 (26.0)	5069 (74.0)	6851
Context			
Continuity of Care (CoC)			
Has regular doctor/GP/NP/PA*	6624 (43.3)	8686 (56.7)	15310
Has regular health care organisation	1103 (66.5)	555 (33.5)	1658
No regular doctor/GP/NP/PA or regular health care organisation	176 (69.3)	78 (30.7)	254
Country			
Australia	726 (34.2)	1398 (65.8)	2124
Canada	1596 (38.6)	2534 (61.4)	4130
France	490 (47.2)	549 (52.8)	1039
Germany	257 (36.7)	443 (63.3)	700
Netherlands	333 (46.8)	379 (53.2)	712
New Zealand	167 (39.7)	254 (60.3)	421
Sweden	3169 (65.7)	1652 (34.3)	4821
Switzerland	551 (44.3)	692 (55.7)	1243
United Kingdom	186 (32.9)	379 (67.1)	565
United States of America	428 (29.2)	1039 (70.8)	1467

* GP = General practitioner; NP = nurse practitioner; PA = physician assistant

Statistical analysis

Only respondents who had a regular professional or organisation for medical care (indicating CoC) were asked to answer questions about Asking_Questions, Explaining, History_Knowledge and Time_Spent. We considered this to be an important aspect for AGP, and decided to analyse the two populations in a logistic regression analysis. In Model 1, we explored all potential determinants except Asking_Questions, Explaining, History_Knowledge and Time_Spent. In Model 2, we used all potential determinants, resulting in an analysis of the subpopulation of respondents who experience CoC. For the interpretation of the results, an odds ratio (OR) can be seen as a measure of the association between an exposure and an outcome. An OR of 1 means that the determinant does not affect the likelihood of the outcome. For the interpretation of our results, we considered determinants with OR ≤ 0.5 or ≥ 1.5, as having relevant (decreasing or increasing) effects on the probability of AGP.

For both models, we analysed the 'missing' data. When considering all respondents and all variables (except Asking_Questions, Explaining, History_Knowledge and Time_Spent), 2.0% of the data were missing; however, when the respondents who answered 'not applicable' were removed, this declined to 1.4%. For the subpopulation of respondents who experienced CoC, the overall 'missing' percentage was 13.6% (6.6% without the 'not applicable' responses). Further analysis suggested that the missing data were randomly distributed; therefore, as a high number of respondents remained, multiple imputation was not necessary and we could focus on a complete case analysis.

Results

Respondent characteristics

The original sample size was 25,530 respondents. We excluded all respondents without one or more chronic condition(s) or who had a missing value for the outcome question of the analysis. In addition, Norwegian respondents were excluded based on the 16% response rate for that country. These adjustments resulted in a final sample size of 17,222 respondents.

Figure 5.1 presents a flow diagram of respondents, while Table 5.1 describes the variables considered to be potential determinants in relation to the outcome variable, AGP. Of the respondents, 34% were 55–64 years old, 37% were 65–74 years old and 29% were 75 or older; 41% were male. Overall, 42% reported having one chronic condition, 32% reported having two chronic conditions and 27% reported having three or more chronic conditions.

Model 1

The prerequisite of a complete case analysis led to a final population for this analysis of 16,881 respondents (98%). Table 5.2 shows the results for Models 1 and 2. Model 1, including all previously determined factors, was statistically significant overall ($p<0.001$). For Model 1, the area under the curve was 0.746 (95% CI: 0.739–0.753).

As shown in Table 5.2, for the whole population (Model 1), there were only three independent variables with an OR ≤ 0.5 or ≥ 1.5: Country (living in Sweden), Information_Exchange_on_Stress and Information_Exchange_on_Diet_and_Exercise. Having no regular professional or organisation had a borderline impact, while the variables with smaller effects on the probability of AGP were Age (>75 years), Gender (male), having three or more chronic diseases, having a combination of mental and one or more somatic diseases, and only having a regular organisation (not a regular professional) for medical care. All countries except for the UK had a lower probability rate for assessing patient goals than the reference country (USA).

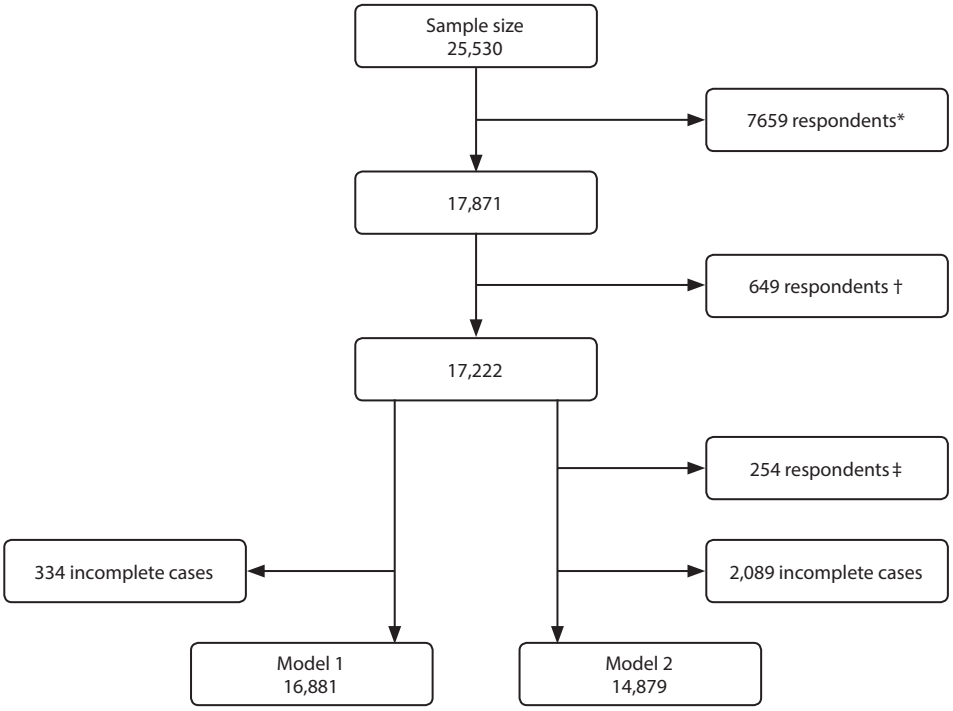

Figure 5.1 **Flow diagram of respondents**

Note: * respondents having no chronic disease or a missing value on the outcome; † respondents from Norway; ‡ Subject not having a regular doctor/general practitioner/nurse practitioner/physician assistant or a regular health care organization

Model 2

For Model 2, 14,879 (86%) respondents were included in the complete case analysis. Model 2 (see Table 5.2) was significant overall ($p<0.001$) and the area under the curve was 0.743 (95% CI 0.735–0.751).

As shown in Table 5.2, for the subpopulation of respondents who experience CoC, the main determinants with OR ratios of ≤ 0.5 or ≥ 1.5 were comparable to the determinants of Model 1. The only exception was the inclusion of Asking_Questions.

The remaining variables with smaller effects also had a comparable direction and size of effects to Model 1 (summarised in Table 5.2). In addition to Asking_Questions, the variables Explaining, History_Knowledge and Time_Spent (specifically explored in Model 2) were statistically significant ($p <0.05$).

Table 5.2 **Logistic regression Model 1 and 2 of possible determinants of the Assessment of Goals and Priorities outcome**

	Model 1		Model 2	
	OR	***p* value (95% CI*)**	**OR**	***p* value (95% CI*)**
Constant	0.77	0.001	0.38	0.000
Age (years)		0.000		0.000
55–64 (1959–1950) †				
65–74 (1949–1940)	1.02	0.583 (0.94 to 1.11)	1.00	0.948 (0.92 to 1.09)
75+ (1939–1906)	0.82	0.000 (0.75 to 0.90)	0.82	0.000 (0.75 to 0.90)
Gender				
Female†				
Male	1.23	0.000 (1.14 to 1.31)	1.21	0.000 (1.13 to 1.31)
Number_of_Chronic_Diseases		0.000		0.000
One chronic condition†				
Two chronic conditions	1.13	0.005 (1.04 to 1.22)	1.11	0.018 (1.02 to 1.22)
Three chronic conditions	1.30	0.000 (1.18 to 1.43)	1.33	0.000 (1.20 to 1.47)
Chronic_Diseases_Type		0.000		0.000
Somatic disease only†				
Mental and somatic disease	0.67	0.000 (0.60 to 0.74)	0.71	0.000 (0.64 to 0.80)
Mental disease only	1.02	0.854 (0.83 to 1.25)	1.03	0.774 (0.83 to 1.28)
Asking_Questions	NA§			
Sometimes/Rarely/Never†				
Always/Often			1.60	0.000 (1.47 to 1.75)
Explaining	NA§			
Sometimes/Rarely/Never†				
Always/Often			1.19	0.016 (1.03 to 1.37)
History_Knowledge	NA§			
Sometimes/Rarely/Never†				
Always/Often			1.18	0.009 (1.04 to 1.34)
Time_Spent	NA§			
Sometimes/Rarely/Never†				
Always/Often			1.18	0.007 (1.05 to 1.33)
Information_Exchange_on_Stress				
No †				
Yes	1.82	0.000 (1.67 to 1.99)	1.74	0.000 (1.59 to 1.91)
Lifestyle_Information_Exchange		0.000		0.000
No exchange†				
Exchange on diet or exercise	1.98	0.000 (1.82 to 2.16)	1.89	0.000 (1.73 to 2.07)
Exchange on diet and exercise	4.20	0.000 (3.86 to 4.57)	3.75	0.000 (3.43 to 4.10)
Continuity of Care (CoC)		0.000		NA ‖
Has regular doctor/GP/NP/PA†‡				
Has regular health care organisation	0.77	0.000 (0.68 to 0.88)		
No regular professional or health care organisation	0.51	0.000 (0.38 to 0.69)		

	Model 1		Model 2	
	OR	***p* value (95% CI*)**	**OR**	***p* value (95% CI*)**
Country		0.000		0.000
Australia	0.82	0.012 (0.70 to 0.96)	0.77	0.002 (0.66 to 0.91)
Canada	0.80	0.001 (0.69 to 0.92)	0.81	0.005 (0.70 to 0.94)
France	0.57	0.000 (0.48 to 0.68)	0.52	0.000 (0.43 to 0.63)
Germany	0.77	0.012 (0.62 to 0.94)	0.76	0.015 (0.61 to 0.95)
Netherlands	0.75	0.005 (0.61 to 0.92)	0.79	0.034 (0.64 to 0.98)
New Zealand	0.71	0.006 (0.56 to 0.91)	0.69	0.005 (0.53 to 0.89)
Sweden	0.32	0.000 (0.28 to 0.37)	0.36	0.000 (0.31 to 0.42)
Switzerland	0.71	0.000 (0.60 to 0.85)	0.68	0.000 (0.57 to 0.82)
United Kingdom	0.99	0.954 (0.79 to 1.25)	0.93	0.548 (0.74 to 1.18)
United States of America†				

* CI = Confidence interval;
† Reference category;
‡ GP = General practitioner;
NP = nurse practitioner;
PA = physician assistant;
§ NA = not applicable. The variables on Professional Attitude and Communication are not applicable to model 1 because they were not used as potential determinants in this analysis.
‖ NA = not applicable. This variable was not included in model 2 because it was not significant.

Discussion

Our study reveals that CoC and information exchange on lifestyle and/or stress are strong determinants of the probability that goals and priorities will be assessed by health care professionals and patient. Patients living in Sweden were less likely to receive AGP than those living in the USA. For respondents who experienced CoC, a professional asking questions was found to be a relevant factor.

Our research has several limitations. First, the response rates differed among countries and were relatively low in general, potentially introducing response bias. Research in Korea using random digit dialling in 2012 and 2014 with a target population of 9,600 community-dwelling adults aged 19–79 years reported response rates of 19% and 16% for landline telephones and 14% and 12% for mobile phones [16]. The response rates for The Commonwealth Fund's survey were higher than in the Korean study, indicating that relatively low response rates are probably to be expected when using this randomisation method; however, the direction of this potential bias is unknown [2]. The weighting of data was not considered to be contributory to our research aim of demonstrating potential associations. Our results provide first insights into the relevant determinants for AGP across countries, but cannot be used to draw conclusions for individual countries.

Secondly, the complexity of the concept of goals must be considered when interpreting the results. In the survey, sharing goals is related to a specific chronic condition(s), with a lack of differentiation between the types of goals; however, as argued in the introduction, disease-specific guidelines are often not applicable to older patients with multiple conditions, and their health-related goals can arise from a variety of dimensions. Moreover, care-related goals for community-dwelling frail older adults are highly individual and relate to well-being as much as to health and functioning [4-7]. This could have led to an underestimation of the sharing of goals.

Furthermore, this is a secondary analysis of the Commonwealth Fund dataset. Ideally, we would have had additional data on the health care professionals involved and on the complexity of care required by the respondents.

Finally, the determinants of the AGP originate from different levels, the macro level, the meso level and the micro level; however, the meso level (the organisational perspective) was not part of this analysis.

Our study also has several strengths. The underlying survey is an international project with a high level of standardisation in content and execution. In addition, although the survey had relatively low response rates per country, the overall population that could be analysed is large. Moreover, despite the widespread avocation of shared decision-making (SDM), there is a general lack of details about goal setting as an autonomous element of an SDM approach, as well as its accompanying barriers and facilitators. This is one of the few

studies to address this knowledge gap.

To the best of our knowledge, there is a lack of research specifically focussed on goal setting with community-dwelling older patients with multimorbidity. Other research has generally focussed on goal setting with seriously ill (hospitalised) patients [17 18] or goal setting in relation to shared decision-making [19-21].

A wide range of patient characteristics influence the demands on health care. Although having more than three chronic diseases was associated with an increase in sharing goals and priorities, while having a combination of a mental and somatic disease was associated with a decrease in sharing goals and priorities, variables in the Patient Characteristics group had less of an impact than expected. For analytical reasons, multimorbidity was defined as having two or more chronic conditions; however, in defining multimorbidity, disease severity and the burden of physiological dysfunctions resulting from the multiple conditions should also be incorporated [22]. These factors together are indicators of the actual complexity of patient health care needs. Although the impact is relatively low, our findings on Number_of_Chronic_Conditions and Chronic_Disease_Type are consistent with multimorbidity as described by Zulman et al. [22]. Age (75+) only had a slight impact. The survey was targeted at *community-dwelling* adults aged 55 or older; therefore, the survey respondents, including those aged 75+, were probably relatively capable of engaging in their own health care. This may explain why, for this population, age had less of an impact on the probability of AGP than expected.

Variables in the Patient-Professional Engagement and Communication cluster appeared to be relevant determinants for this analysis. Although we cannot draw conclusions on causality, these findings provide initial insights into possible future engagement points, especially when focusing on potential barriers. Information exchange regarding lifestyle and/or stress has a large impact on AGP; however, a study on lifestyle consultations by Dutch general practitioners and practice nurses found that information about lifestyle is mostly given in generic terms and not tailored to the specific patient [23].

Country is a strong contextual determinant. This could be an effect of certain characteristics of different health care systems, cultures or other factors, which complicates the interpretation of this finding; for example, Swedish clinicians mentioned that the remuneration system does not allow them to spend enough time on communication, instead emphasising easy accessibility, rapid turnover and reduced performance time [24].

From our analysis, it appears that CoC is a relevant determinant, which is in line with the findings of Kohnke and Zielinski [25] on the association between CoC and the utilization of Swedish primary care emergency services. Incidence rate ratios suggested that patients with the lowest CoC had a higher number of emergency services visits compared with those experiencing the highest CoC [25]. Furthermore, Hultberg and Rudebeck [26] investigated patient participation in decision-making about cardiovascular preventive drug treatments

through the resistance to treatment proposals in Sweden, concluding that the decision-making process extends beyond single encounters, which underpins the importance of CoC. Other studies found that CoC with a general practitioner is associated with lower health care costs, higher patient satisfaction and improvements in patient health [27 28]. CoC in general practice is also associated with reduced hospital admissions, especially among heavy users of primary care [29]. The potential contribution of goal setting to these effects is not yet clear.

Other studies have found that time constraints are an important barrier to shared decision-making and goal setting [19 30 31]. In this analysis, Time_Spent was an assessment of whether the respondents thought health care professionals spent enough time with them. In this sense, in line with Osborn et al. [15], Time_Spent is a variable of patient engagement rather than a contextual factor.

Our research has several implications. To facilitate the consideration of different types of goals in future research, survey questions about different types of goals and specific health care professionals could be added to increase the representation of a goal setting focus in daily practice. Furthermore, survey questions on the complexity of health care needs should be added to increase the representation of patients who would probably benefit most from goal setting. Further research based on our findings could consider the determinants and their underlying causal relationships to provide health care professionals and policymakers with engagement points for realising patient goal-oriented health care.

In conclusion, our analysis shows that patient-professional engagement and communication and contextual factors are related to the probability of AGP. It also indicates that AGP is most likely to occur in consultations where a health care professional asks questions and exchanges information about stress and lifestyle with a patient, though this still varies greatly by country. Considering the context, CoC differences between countries appear to be a relevant factor in explaining the likelihood of AGP, while patient characteristics have less of an impact than might be expected. Quality of care projects may be stimulated to reduce the substantial international variation in this very relevant aspect of setting health care goals and priorities with older adults.

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Additional files

Additional file 5.1 **Response rates by country** [2]

Australia	31%
Canada	28%
France	29%
Germany	26%
Netherlands	25%
New Zealand	27%
Norway	16%
Sweden	23%
Switzerland	60%
UK	23%
USA	24%

CHAPTER 6

Summary and General Discussion

In this final chapter, we summarise and discuss the main findings of our study, report on methodological strengths and limitations, discuss implications of our findings for clinical practice, health policy and for further research and draw general conclusions.

Summary

Person-centred care approaches are essential to address the highly variable needs of patients with multimorbidity [1 2 3 4]. SDM can be seen as fundamental to PCC [5], however, the SDM model, which was mainly developed in cure situations in hospital settings may be deficient in more complex care situations [6]. In the introduction we considered the main focus of current medical practice, challenges due to multimorbidity, and difficulties in incorporating preferences and values, factors related to deficiencies in the current SDM approach. To address the challenges of decision-making with older patients with multimorbidity, a transition from a disease-specific to a goal-oriented approach in decision-making is necessary [7 8].

Our study was designed to investigate goals and GS in relation to SDM in the context of patient goal-oriented health care. For this thesis, four research objectives and four research questions were defined as summarised in Box 6.1.

Box 6.1 **Research objectives and research questions**

Research objective 1
To analyse the concept of goal setting in the context of shared decision-making.
- What are clinicians' views on the concept of goal setting in the context of SDM? (RQ 1)

Research objective 2
To improve the knowledge base for the concept of goal-orientation and types of goals in decision-making.
- What are clinicians' views on goal-orientation in the context of CGS and SDM? (RQ 2)

Research objective 3
To evaluate the availability and effects of interventions on collaborative goal setting.
- What are effective interventions in supporting collaborative goal setting or health priority setting? (RQ 3)

Research objective 4
To identify possible factors having impact on sharing goals in daily practice.
- Which characteristics of patients, patient-professional engagement, communication and context factor have impact on the probability that health care professionals will discuss goals or priorities with older patients with chronic diseases? (RQ 4)

Overview of main findings

Our study contributes to further development of goal-oriented health care with older patients with one or more chronic conditions from two perspectives: clinical practice and theory development. Research objectives 1 and 2 aimed at theory development, objectives 3 and 4 were oriented at clinical practice. Figures 6.1, 6.2, 6.3 and 6.4 provide an overview of the thesis building on the outline illustrated in Figures 1.1 and 1.2.

Figure 6.1 **Thesis overview research question 1**
Note: This figure provides an overview of the main findings of the first research question which focused on further theory development.

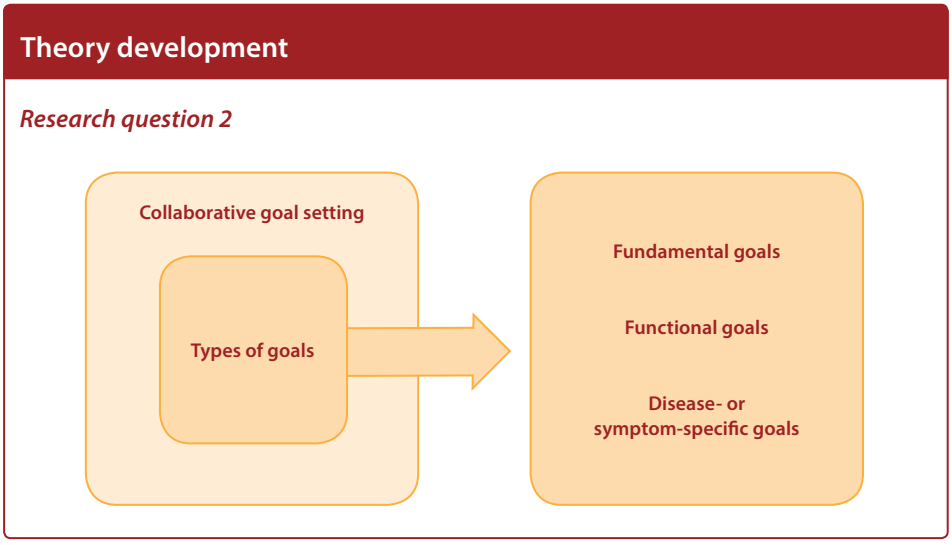

Figure 6.2 **Thesis overview research question 2**
Note: This figure provides an overview of the main findings of the second research question which focused on further theory development.

Goal setting and goal-oriented SDM (chapter 2)

SDM and goals are important concepts in patient goal-oriented health care. However, their interrelatedness was not yet clear. Based on a framework analysis of 33 interviews of CGs and GPs we researched these clinicians' perceptions of the concept of goal setting within the context of SDM (chapter 2). Considering our first research objective, we found that 16 clinicians mentioned 'goal setting' as an integrated element of SDM.

Seventeen clinicians (6 GCs and 11 GPs) did not mention 'goal setting' as an explicit component. Our analysis revealed two potential reasons for this observation. Next to the use of other terminology, part of these clinicians viewed CGS and SDM as separate but related processes. Based on our results, we concluded that models of SDM that do not contain an explicit GS element are deficient and have overlooked an important aspect of engaging patients in decision-making.

Types of goals and goal-orientation in the context of SDM (chapter 3)

In chapter 3 we researched the perspectives of CGs and GPs, both involved in decision-making with older patients with multimorbidity, on types of goals and goal-orientation in the context of SDM by thematic analysis of 33 interviews. Considering our second research objective, we developed a three-goal model consisting of disease-specific or symptom-specific goals, functional goals and fundamental goals based on our analysis of goal-orientation of CGs and GPs. This three-goal model may provide an important guide for CGS in clinical practice. We introduced the concept of 'fundamental goals' meaning goals specifying a patient's priorities in life, such as their values and core relationships, topics that serve as reference points for decision-making. Clinicians differed in their consideration of fundamental goals, constituting three categories: clinicians with a primary focus on functional goals and/or disease-specific or symptom-specific goals; clinicians implicitly considering fundamental goals and clinicians with explicit consideration of fundamental goals. The analysis revealed several reasons for the added value of eliciting and using fundamental goals.

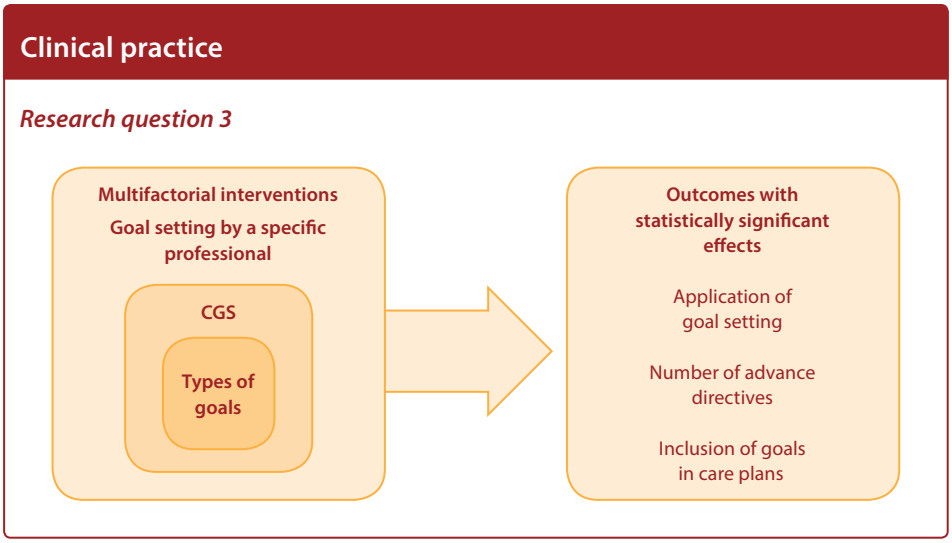

Figure 6.3 **Thesis overview research question 3**
Note: This figure provides an overview of the main findings of the third research question which focused on clinical practice.

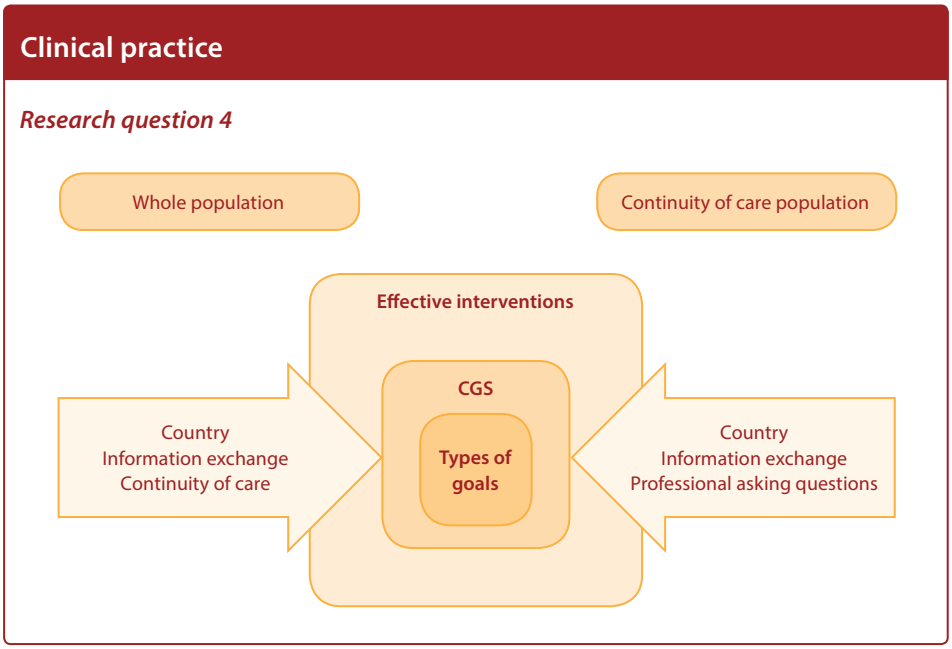

Figure 6.4 **Thesis overview research question 4**
Note: This figure provides an overview of the main findings of the fourth research question which focused on clinical practice.

Clinical practice of sharing goals (chapters 4 and 5)

The third and fourth objectives, to evaluate the availability and effects of interventions on CGS and to identify possible factors having impact on sharing goals in daily practice, were addressed in chapters 4 and 5. Considering daily practice of sharing goals, chapter 4 researched effective interventions supporting CGS or health priority setting by means of a systematic review of the literature (research question 3). In chapter 5 on the Commonwealth Fund survey (CWF) we empirically analysed factors having impact of sharing goals with older patients with a chronic disease or multimorbidity (research question 4).

The systematic review of the literature on effective interventions supporting CGS or health priority setting (research question 1), considered a study population of patients having at least one chronic condition or more with a mean age ± standard deviation (SD) including the age of 65 years. No distinction in setting of care was made. Considering goal and/or priorities, the interventions targeted: 1. health and treatment priorities (Preferences in treatment planning for older patients (PrefCheck) intervention), 2. highest priorities for optimizing health and quality of life (Guided Care intervention), 3. both goals and advance directives (Helping Older People Experience Succes (HOPES) intervention), 4. personalised goals (Collaborative Care Model) and 5. priorities and goals (Integrated Systematic Care for Older PEople (ISCOPE) intervention). In none of these interventions goals and priorities were further specified.

Considering effective interventions supporting CGS we concluded that this was a relevant but 'early' topic. Most interventions were multifactorial interventions. Although this was no selection criterion, we only found interventions in non-hospital settings. Common promising components for further development of multifactorial interventions were: explicit attention for GS or priority setting by a specific professional, involvement of caregivers and training and education of professional and patient and care planning.

To answer research question 4, we assessed the impact of patient characteristics, patient-professional engagement, communication and context factors on the probability that health care professionals will discuss goals or priorities. In the CWF survey community-dwelling patients aged 55 or older were included. Having at least one chronic condition was a prerequisite for respondents to answer the survey question which was used as outcome question. No distinction was made in care setting.

In the CWF analysis we built two logistic regression models: *model 1* including the whole population and *model 2*, including only those respondents experiencing CoC. Country and CoC, information exchange on stress and lifestyle and a professional asking questions (in case of CoC), had the largest impact. Patient characteristics, like age, had less impact as expected beforehand.

Considering our third and fourth research objectives we can draw the following major conclusions. First of all, single interventions regarding CGS and/or priority setting are rare.

They are usually components within varying multifactorial interventions. CGS and/or priority setting can probably best be integrated in complex care interventions. Secondly, the multifactorial interventions identified, had statistically significant effects on the application of GS, the number of advance directives, or the inclusion of problems, goals and actions in care plans. Although potential causality needs further research, elements associated with the likelihood of sharing goals, based on our systematic review and secondary analysis of the CWF data, are: CoC and explicit care for GS or priority setting by a specific professional; a patient-centred attitude in communication, 'asking questions' and information exchange; involvement of care givers; training of intervention health care professionals; care planning and country.

Discussion

Reflections on the main findings

We will start our reflections on the main findings by elaborating on differences in types of goals between our various studies to give context for interpretation. We continue by relating our findings to the theoretical context of Evidence Based Medicine (EBM) and PCC, and with a reflection on recent developments in guideline principles and guidelines for quality of care for older patients with multimorbidity in the context of our results. We specify these developments to views on the Dutch situation. Following this reflection on the broader context of our results we will propose a further development of the three-talk SDM model to strengthen the goal-orientation of a shared decision-making approach. We end this reflection on main findings by an elaboration on potential influencing factors in future developments towards integration of CGS and SDM.

Different studies consider different types of goals

As visualised in Figures 6.1 to 6.4, for this thesis we aimed to combine research focusing on theory development (chapters 2 and 3) and practice-oriented research (chapters 4 and 5). Following from our study on goals and goal-orientation, distinct types of goals exist. We developed the three-goal model considering three types of goals, including the new concept of fundamental goals. However, in our systematic review and CWF analysis we could not distinguish between different types of goals. The systematic review (chapter 4) evaluated interventions on CGS and /or priority setting without distinguishing between different types of goals, resulting in the fact that for interpretation of promising components for developing a CGS intervention based on this research, we cannot distinguish between disease-or symptom- specific and functional goals. This also means that we do not know whether these are relevant factors for CGS on fundamental goals. The secondary analysis of

CWF data in chapter 5 (research objective 4), considered a discussion between patient and health care professional of main goals or priorities in caring for a certain condition. These goals and priorities were not specified further, which means that for the interpretation of these findings again we cannot distinguish between different types of goals when interpreting the factors having impact on the probability that health care professionals will discuss goals or priorities. Furthermore, the framework analysis on GS in the context of SDM (chapter 2), also does not distinguish between different types of goals. It is important to keep this in mind when interpreting and relating the findings of the individual studies.

Evidence based medicine, patient-centred care and shared decision-making

In care for older patients with multimorbidity, the developments towards a patient goal-orientation in decision-making and the developing awareness that a SDM approach needs GS as essential element, can be related to both EBM as well as PCC.

Decision-making in EBM is based on three pillars: 1. Clinical expertise of the professional, 2. Context and individual preferences of the patient and 3. Scientific evidence [9]. Although the involvement of patients' context and individual preferences was gradually made explicit in the development of EBM from a retrospective view [10], in essence, EBM focuses on individual patients, answering the question of what is the best course of action for this individual patient considering all relevant aspects [11]. In EBM, after finding and appraising the evidence applicable and integrating its inferences with their expertise, clinicians attempt decisions that reflect their patients' values and individual context [12]. However, incorporating patient values, preferences and circumstances is a difficult step in the decision-making process [12]. In this context, Mulley et al. (2012) [13], earlier introduced the concept of 'preference diagnosis'; 'an inference of what a patient would choose if her or she were a fully informed decision maker'. In medical decision-making, an accurate preference diagnosis is as important as an accurate medical diagnosis. However, as argued by Mulley et al., preference misdiagnosis often goes unnoticed. In addition, incorporating a preference diagnosis, and thus a patient's personal context and individual preferences in decision-making appears to be complex. So far, it was unclear what approach could be used to elicit and integrate patient values, context and preferences in decision-making in a striving for patient-centred care.

Patient-centred care is defined as health care that is 'respectful and responsive to individual patient preferences, needs, and values and ensures that patient values guide all clinical decisions' [3]. The American Geriatrics Society emphasises a person-centred approach that includes patient preferences and current medical conditions in its guiding principles for the care of older adults with multimorbidity [14]. Person-centred care should align health outcomes with individuals' values and goals [15]. At the patient-professional level, PCC needs a strong patient-professional relationship which is built on communication, respect, shared responsibility, and support for the patient as a whole person [3 16]. At the system level, a

patient-centred approach can address poor care coordination issues experienced by complex patients [17]. PCC approaches can be seen as crucial to address the needs of this patient population [1 2].

SDM can be seen in the context of PCC as well as in the context of EBM. SDM fits into this perspective of PCC [18] and can even be seen as fundamental to PCC [5]. Several relevant components of PCC are also components of SDM: e.g. the clinician-patient relationship, the provision of patient information, the explicit patient involvement in care, the involvement of family and friends and patient empowerment [19 20]. In the context of EBM, SDM is described by Greenhalgh et al. [11], as 'finding out what matters to the patient –what is at stake for them- and making judicious use of professional knowledge and status (to what extent, and in what ways, does this person want to be 'empowered'?) and introducing research evidence in a way that informs a dialogue about what best to do, how, and why.'

As we concluded in chapter 5 actual models of SDM could be improved by adding an explicit GS component. Incorporating GS into SDM makes the involvement of a patient's context and individual preferences concrete and explicit, thereby linking to EBM. In PCC the clinician-patient relationship, the provision of patient information and the explicit patient involvement in care, are key components, which is in line with our research concluding that CoC, especially a professional asking questions and information exchange, increases the likelihood of sharing goals. In our view GS can be seen as an example of an essential ingredient of PCC. The incorporation of GS into a SDM approach strengthens the patient orientation of SDM. Other research mentions both values and goals as potential input for decision-making processes [6 15 21]. As a further elaboration on the notion of the relevance of values for decision-making as input giving factor, we introduced the concept of fundamental goals. Values, personal history and core relationships can be operationalised by CGS of fundamental goals. In this way, fundamental goals can function as anchor points for GS of other types of goals and for decision-making in general.

In our view, our research contributes to both EBM and PCC by providing an approach for involvement of patient values, preferences and context through the distinction of several types of goals, the incorporation of GS into SDM and providing first insights in facilitating factors for GS.

Guideline principles and guidelines for quality of care

At both a national level as well as at an international level, views on quality of care of older patients with multimorbidity are developing rapidly. Considering these developments, we want to discuss the guideline principles on the care of older adults with multimorbidity of the American Geriatrics Society [22], the Ariadne principles for primary care [23] and the National Institute for Health and Care Excellence (NICE) quality standard and guideline on multimorbidity [24 25].

In 2012 the American Geriatrics Society Expert panel, published guiding principles on PCC for older adults with multiple chronic conditions, stating that 'clinicians need a management approach that will consider the challenges particular to each individual, including the often-limited available evidence; interactions among conditions or treatments; the patient's preferences, goals and prognosis; multifactorial geriatric problems and syndromes; and the feasibility of each management decision and its implementation'. One of the guiding principles is eliciting and incorporating patient preferences into medical decision-making [22], especially in case of preference-sensitive decisions. Preference elicitation means the voicing by individuals of their opinions about treatment options and potential outcomes based on personal values and priorities. The sharing of decision-making is mentioned.

These guideline principles for the care for older adults with multimorbidity inspired the development of the Ariadne principles to provide orientation in decision-making in multimorbidity during primary care consultations, which were published in 2014. The central principle is the sharing of realistic treatment goals by physician and patient. These treatment goals are the result from an interaction assessment of conditions and treatments, consultation and context, and a priorisation of health problems that takes into account patient preferences. In making health care decisions, patients' values and preferences need to be taken into account. Individualised management to determine the best options of care to achieve these goals and goal attainment evaluation are other aspects. To meet the shared treatment goals, a care plan is made, which sets out monitoring, treatment, prevention and self-management advice to attain the treatment goals. New or changing conditions should trigger the (re)start of the process. Careful coordination of care is important to ensure continuity [23]. Values and patients' preferences are taken into account when prioritising and setting treatment goals. Treatment goals are part of the care plan, which has a dynamic nature. Considering interprofessional collaboration, the importance of careful coordination of care and continuity is emphasised. The sharing of treatment goals is mentioned in the discussion of the Ariadne principles.

The National Institute for Health and Care Excellence (NICE), an institute of the National Health Service (NHS) in England, published a quality standard on multimorbidity (QS153) and a guideline on multimorbidity and clinical assessment and management specifically (NG56) [24 25] in 2016 and 2017. The NICE guideline NG56 builds on well-established geriatric principles as formulated by the American Geriatrics Society and principles of primary care practice articulated in the ARIADNE principles [23 26]. The NICE guideline presents a framework based on increasing complexity of needed care, and provides guidance on how to identify patients who would benefit. According to the NICE guideline an explicit decision should be made as to how and when single disease guidelines should be applied [26]. In the quality statement of QS153 it is stated that adults with an individualised management plan for multimorbidity are given opportunities to discuss and review periodically their

quality of life, their values, priorities and (future life) goals with a member of their care team. However, there is no advice on methods to have this discussion [24 25]. Goals and plans for future care (including advance care planning) should be agreed upon and written in an individualised management plan. In the guideline, nor in the description of the 'individualised management plan', nor in the description of 'establishing patient goals, values and priorities', SDM is explicitly mentioned.

Considering recent developments in views on quality of care of older patients with multimorbidity, based on the guideline principles on the care of older adults with multimorbidity (American Geriatrics Society), the Ariadne principles for primary care and the NICE quality standard and guideline on multimorbidity, we can draw several conclusions. First of all, clinicians are advised to make use of care plans with a dynamic character, taking account for changing conditions. Our finding of care planning as a factor having impact on the likelihood of sharing goals, is in line with this recommendation. Furthermore, these guidelines and guideline principles emphasise the incorporation of patient values, preferences, goals, priorities, quality of life and/or future life goals in decision-making as an element of quality of care, which is in line with our research. However, from these guideline principles and guidelines the distinction between these elements is not clear, let alone practical approaches for incorporation of these elements. Our systematic review on GS and priority setting revealed a relative lack of practical approaches of GS, a primary integration of GS into multifactorial interventions and no clear distinction between different types of goals. Furthermore, the sharing of decision-making or treatment goals is mentioned, however, in the literature analysed and discussed in this section, SDM as such was not mentioned and a clear link between GS and decision-making was also not given. Finally, it is also not clear in what way patient values should be practically incorporated in the process. Based on our findings, we argue that guidelines could be developed further by recommending an adapted form of a SDM approach, including CGS of different goal types to align terminology and further concretise the incorporation of values, goals, preferences and context.

Recent developments in views on SDM in the Netherlands

In the Netherlands both GPs and CGs care for community-dwelling older patients. In the Netherlands, as evaluated by Van der Weijden et al. [6], SDM is 'booming' among the Dutch government and policy makers. Initiatives targeted at implementing SDM are supported by the Dutch government, the Ministry of Health, the Federation of Patients' Organisations, professional bodies and health insurers. Van der Weijden et al. argue that a 'goal talk' is essential to deal with uncertainty and to prevent the default model of the informed patient model, which can be summarised as: 'here is the information on the options, let me know what you decide', and which transfers health care professionals' uncertainty, responsibility

and decisional stress to patients. Van der Weijden et al. argue that in SDM an additional *preceding* step with shared goal setting, a 'goal talk', seems justified. The authors state: 'Every time again, for each decision knot the clinician and patient first prioritise the most urgent problems and the patient's goals for quality of life, before decisions are taken on how the problems are to be managed and how the patient's goals are to be reached. Graphical tools have been developed to support goal talk, based on the WHO International Classification of Functioning, Disability and Health (ICF).' The stated necessity of integrating GS to a SDM approach is in line with our findings.

Goal-oriented shared decision-making: towards a next model for daily practice

As we strive for an evolvement of health care from a disease-specific to a patient goal-oriented approach in SDM, explicit GS can be the key factor in aligning diagnostic and therapeutic options with older patients' values, needs and priorities. Recently Elwyn et al. [27] proposed a revised three-talk model for shared decision-making, building further on the previous model, which consisted of a Team Talk, Option Talk and a Decision Talk [28 29]. In the revised model, the Team Talk emphasises that patient and health care professionals work together. The Team Talk consists of three elements: 1. Indicate choice, 2. Provide support and 3. Identify goals and explore patients' overall goals in relation to their health issue, especially as decision-making relies so much on long term objectives. The relevance of goals and goal setting for decision-making and the inclusion of goals and/or goal setting in the Team Talk is a confirmation of the research for this thesis.

The three-talk model for SDM is developed for SDM in general. In the paper of Elwyn et al., goals and goal setting as an element of the Team Talk are described as 'eliciting goals', 'asking about goals' and 'identifying goals and exploring overall goals'. For use in the context of shared decision-making with older patients with multimorbidity, we propose that a further specification of 1. different types of goals based on the three-goal model and 2. clarification on the (collaborative) goal setting process could have added value for this three-talk SDM model to increase a goal-orientation in SDM with older patients with multimorbidity.

As a next step towards a goal-orientation in shared decision-making with elderly with multimorbidity, we propose the further development of a goal-oriented shared decision-making (G-SDM) model by the integration of the three-goal model into the three-talk model, as a model for further research. In our view, the goal setting element would consist of two phases. In phase one, patient and (coordinating) health care professional engage into a goal setting process, based on the three-goal model (chapter 3), considering and tuning goals at three levels, namely fundamental goals, functional goals and disease- or symptom-specific goals. First, fundamental goals are elicited. This means that a patient's values, personal history and individual priorities in quality of life are specified, made explicit, including

trade-offs, and operationalised in (a) fundamental goal(s), which can be seen as the 'patient's overall goals in relation to their health issue'. Secondly, functional goals are set in relation to fundamental goals. Step three consists of setting disease-specific and/or symptom-specific goals in relation to functional and fundamental goals. Defining goals as concrete as possible is important. Aspects like mental competence, influence and representation by family members and permanence and stability of goals have to be taken into account. Although all goals are basically elicited jointly, the weight of the patient's, caregiver's and health care professionals' input may vary depending on a patient's condition as well as their circumstances and preferences in involvement. The alignment and collaboration of involved health care professionals is important and could be done by the coordinating health care professional. Fundamental goals do not have to be discussed again in every consultation, provided that they have been discussed and documented explicitly in an earlier step and that no fundamental changes in the patient's condition or their circumstances have occurred. In the second phase of goal setting, patient and clinician(s) determine priorities in goals. Which goals should be given priority for a specific problem and decision for this patient? This leads to decision specific goals, which are input for the rest of the process, starting with the Team Talk, and followed by the Option Talk, discussing alternatives using risk communication principles, and the Decision Talk, getting to informed preferences and making preference-based decisions. Goals provide input for and support these Talks. In this way SDM results in goal-oriented decisions. Essential for this model is its cyclical and dynamic nature that enables the adaptation of goals and decisions if necessary. The section *Implications and recommendations for clinical practice,* provides a case example of the application of this G-SDM model.

Furthermore, following further development towards a G-SDM model, we propose to outline terminology as follows. Fundamental goals, functional goals and disease- and/or symptom-specific goals are set in the first phase of goal setting in an interrelated goal setting process. In fundamental GS patient *values*, *quality of life* and/or *future life perspectives* are translated and operationalised in *fundamental goals*. *Treatment (and diagnostic) goals* can be *disease-or symptom-specific* or *functional goals. Priorities* in (treatment (and diagnostic)) goals are set in the second phase of the goal setting process. *Options* for diagnostics and treatments are discussed in the Option Talk. *Preferences* for diagnostic, treatment and/or care options in the context of prioritised goals are discussed in the Decision Talk.

Relevant factors for a development towards goal-oriented shared decision-making

In the context of national and international developments in the care for older patients with multimorbidity, without striving for completeness, we would like to discuss three levels of factors which we consider relevant in developments towards and the implementation of a G-SDM approach:

- The micro level: The patient and clinician relationship and clinician's attitude
- The meso level:
  - Health Information and Communication Technology (ICT)
  - Guidelines and quality metrics
  - Care planning and continuity of care
- The macro level: Societal factors

The micro-level: The patient and clinician relationship and clinician's attitude

Goal-oriented shared decision-making happens in the interaction between patient and clinician and in some cases a care taker and several clinicians. At the micro-level of the interaction between clinician and patient, the personal relationship between patient and clinician and a clinician's attitude can be seen as potential influencing factors in developments towards G-SDM. For both EBM and PCC a strong personal relationship between patient and clinician is important [3 11]. For SDM a long-standing relationship between clinician and patient can be a facilitating factor, although such a relationship is not compulsory [30]. From our research it followed, that a patient-centred attitude in communication through 'asking questions' and 'information exchange', increased the probability of the sharing of goals. We hypothesise that a strong personal relationship between patient and primary clinician is a facilitating factor for goal-oriented SDM. It is an interesting question whether this has to be the primary clinician or that this also can be done by other health care professionals.

Earlier research contributed to knowledge on clinicians' attitudes towards SDM. In daily practice 'sharing' of decision-making, meaning the leeway and responsibility given to the patient for making the decision, varies [31]. Many clinicians think they practice SDM, but evidence suggests a perception-reality gap [32], because of misconceptions about the nature of SDM, required skills and time, and the degree to which patients, families, and carers wish to share in SDM [33]. Fried et al. [31] argued that the higher the uncertainty surrounding the options and the greater the clinician's ambivalence about the 'right' choice, the higher the probability that the patient will be asked to make the decision. Conversely, clinicians are more likely to make strong recommendations if decision's outcomes can be predicted more precisely. Fried et al. argue that decisions without clear information and with a lot of uncertainty, are the most difficult to make. Involving a patient's personal preferences and priorities, a core element of SDM, is always relevant for all decisions, no matter the base of evidence. Patients can have other priorities than clinicians. In decisions with a lot of uncertainty, the involvement of the clinician might be even more important to be able to give the patient a clear picture of all the (un)available information and trade-offs.

Clinicians differ in their attitude towards SDM. For many clinicians SDM is regular clinical practice, at least in preference sensitive decisions, but for others it is seen as 'just a fashionable phrase to be followed by business as usual' [34]. Clinicians differ in their views on

the added value of SDM [34-38]. Hesitation for SDM was felt among part of Dutch clinicians, who are challenged by many new tasks [6]. A reserved attitude of clinicians towards a SDM approach can be an important barrier for further implementation of SDM.
We hypothesise that CGS and the incorporation of goals in decision-making could contribute to further development of a decision-making approach to handle complexity in decision-making, constituted by multimorbidity, lack of information and uncertainty and patient involvement, thereby potentially helping to increase the applicability and added value of SDM for patient and clinician.
In general, the implementation of SDM is not easy and clinicians need the skills and tools to do it and to build trust and patients are in need of information and support [11 39]. Our research revealed that training of intervention health care professionals was a common potential facilitating factor in GS and/or health priorities setting interventions and we hypothesise that education and training will also be a facilitating factor for goal-oriented SDM.

Prerequisites at the meso-level
To develop a goal-orientation in health care, health ICT is a key factor. Needed adaptations in guidelines and quality metrics and care planning and continuity of care are relevant factors in isolation, but these factors are also dependent on good health ICT infrastructure and implementation.

Health Information and Communication Technology (ICT)
Health ICT can be seen as a facilitating factor for further development of patient goal-oriented care. Chances lie at the fields of personalisation of diagnostics, and treatment, personalisation of goal setting and goal (attainment) evaluation, optimisation of research, performance measurement, clinical practice guidelines and quality metrics and care planning and continuity of care.
The availability and analysis by artificial intelligence of big data on patients' experiences, treatments and outcomes could be useful in personalising care for individual patients, in the sense of medically targeted at this patient's medical history, actual conditions, actual need, context, competencies, risk aversiveness, willingness to invest in his/her own health et cetera. Furthermore, possibilities of personalising care in the sense of aligned with a patient's personal goals are also developing. Goal setting and goal (attainment) evaluation of different interrelated functional and disease-and/or symptom-specific goals by using digital medical decision support systems are probable future steps. Clinical decision support at the point of care might facilitate SDM, assuming that decision-making accounts for goals and preferences across conditions instead of within a single condition [26]. In patient-centred registries patient outcomes and experiences as well as other valuable data, are continuously monitored and available in real time to both clinicians and patients to facilitate their joint work [40]. Some

registries are gaining capacity to collect data on patients' priorities and support care in real time [40]. Digital biomarkers collecting data on behaviour and physiological measures collected through connected digital tools can be valuable data sources, especially if integrated with clinical data collection. Opportunities for personalisation of goals and treatment, will increase by further developments in instant feedback loops and feed forward possibilities facilitated by profound and instant analysis by artificial intelligent solutions. Data are explicitly collected with a view to multiple uses and can be repurposed to support service improvement and scientific research [41]. If care and decision support systems are made suitable and available to patients, patients can be supported in further engagement in their own care.

Considering treatment evaluation and performance management, performance measures also need to take into account multimorbidity. One method for incorporating comorbidity interrelatedness into performance measurement would be weighting clinical care based on the complexity of management decisions and/or the clinical benefit to an individual patient [42]. In this line patient value-based health care could be introduced, defined as the achievement of each patient's highest-level health outcome goals given the workload each is willing and able to perform [43]. GS and goal attainment supported by health ICT are essential for this individualised approach to quality of care in the context of performance management.

In our view, these developments in health ICT provide enormous chances for GS, the measurement of goal attainment and SDM. However, as becomes clear from the challenges described, ICT is no silver bullet and needs certain prerequisites. There are challenges in the availability, analysis and usability of data in the fields of: timing of feedback of data to clinical practice lags behind actual care, manual entry of data, single use of data instead of multiple purposes, no patient involvement in determining priorities in data collection, and very important for this research, patients not having access to data collected or opportunities to add data outside medical encounter and thereby not being able to use data for self-management or SDM [41]. Additional challenges are: professional and patient burden of administration including feasibility of self-and proxy-reporting, and degree of expertise needed for interpretation [44]. Societal factors in this context are discussed as a separate and third factor in this discussion of prerequisites at the meso-level.

Clinical practice guidelines and quality metrics

Clinical practice guidelines (CPG) and quality metrics are developed to improve supply and evaluation of quality of care. In general, current practice guidelines and quality metrics constitute a barrier to the implementation of a patient goal-orientation of care [43], because they still remain disease-centric, potentially constituting impractical, irrelevant or even harmful care to patients with multimorbidity [45 46].

Optimising CPGs to take into account multimorbidity and complexity of context is necessary, however in our view there are three guiding principles to do that. Optimising regular

guidelines to take into account complexity, personalisation of advice by advanced data analysis and the development of a meta-guideline on GS and goal attainment as guiding principles. Probably these will be complementary.

Clinical guidelines could be adapted to provide recommendations about best care practices when a patient has clinically relevant co morbid conditions, i.e. conditions that are likely to alter a patient's clinical course or his or her ability to achieve treatment benefit [22 47-49]. Specific clustering of conditions could be incorporated in guidelines [50]. Furthermore, Uhlig et al. [46] developed a framework for crafting CPGs that are relevant in the care and management of people with multimorbidity. Additionally, it could be helpful in the development of CPGs to conduct systematic reviews of patient values and preferences in specific content areas and use these in the development [51].

Furthermore, further developments in advanced (big) data analysis by artificial intelligent systems may constitute opportunities for a transition from disease-oriented guidelines into more patient-centred (even personalised) guidelines that take into account individuals' multiple interacting health problems and quantify the potential risks and benefits of alternate treatment options [42].

In a meta-guideline, the starting point would be complexity at several domains. CGS, care planning and goal attainment evaluation would be central meta-guideline elements. Collaborative goals could constitute a personal framework to provide care which is fit to that person, his/her condition and context. In this way a patient's health is redefined in terms of this individual patient's goals. Such an approach would give insights in the complexity of care for a certain patient and, especially with health ICT support (and personalised, patient-centred advice on diagnostics and treatment), could result in a goal-oriented evidence-based care approach. A prerequisite for this approach is that, when applied, it should allow for clinical decisions to be inconsistent with current disease guidelines [52]. Based on a thorough meta-guideline process, this can be made clear and substantiated, contributing to transparency. Other research used this perspective of GS and goal attainment as central elements, in a view on quality metrics, namely: for the evaluation of quality of care provided, replacement of disease-centric with patient-centric quality metrics such as individual goal elicitation and attainment and ascertainment of treatment burden and functional status could be helpful [7 52]. We think that a meta-guideline on GS and goal attainment could have added value in linking disease specific guidelines and goal-oriented quality metrics.

Care planning and continuity of care

Effective care for people with multimorbidity needs dynamic individualised care plans [53]. From our analysis it followed that care planning is a potential factor increasing the likelihood of sharing goals. We do not know whether this association is caused by sharing goals being an essential element of care planning or whether the sharing of goals is followed by care

planning. According to Edwards et al. [54] defining and integrating patient goals via care planning tools is a key element of care planning. In this way, a care plan can be a useful tool to define and integrate patient goals, also contributing to defining and evaluating quality of care for a specific patient. Following Edwards et al., we hypothesise, that care planning is a facilitating factor for goal sharing. It is essential that care planning should not create an additional burden for clinicians and patients, with no perceptible benefit [55].

Health ICT and cloud-based sharing can provide tools to coordinate care and share care plans developed in partnership with patients. Ideally, care plan tools would facilitate GS and iterating and measuring progress over time, by being living documents that automatically pull prioritised and relevant data [54 56]. By leveraging the ability to collect actionable patient data before the visit and ensuring that these data are easily available during the visit, health IT tools can be used asynchronously, thereby having the potential to improve the quality of care interactions for complex patients [57]. An example of GS by an eHealth tool is the Electronic Patient Reported Outcome (ePRO) tool. This tool is designed to overcome challenges in health care delivery to people experiencing complex chronic disease and disability (CCDD) by supporting goal-oriented primary care delivery. Using the tool, patients and clinicians collaboratively develop health care goals on a portal linked to a mobile device to help them track progress between visits [16 58].

CoC and explicit care for GS or priority setting by a specific professional were both associated with GS between patient and professional. In our research (chapter 4) CoC reflected continuity in health care professional and/or health care organization. Haggerty et al.[59], describe the achievement of CoC by bridging discrete elements in the care pathway – whether different episodes, interventions by different providers, or changes in illness status – as well as by supporting aspects that endure intrinsically over time, such as patients' values, sustained relationships, and care plans. For continuity to exist, care must be experienced as connected and coherent'. The experience of CoC may differ for clinicians and patients.

When having multiple chronic conditions, most of the times, several clinicians are involved and concentrate on managing different conditions and monitoring different disease-specific outcomes. In general, even in integrated health care systems, clinicians independently determine desired outcomes within the context of their own specialty [60]. Patients with complex multimorbidity often see many different health care providers working across multiple sites [61]. Communication between providers is frequently suboptimal, which can impact negatively on patient outcomes [2]. Patients are at risk of receiving fragmented care which is not always focusing on what matters most to them [61].

One approach for improvement is for clinicians to refocus care from treating individual diseases in isolation to a focus on care in which all clinicians integrate their care to meet patients' specific, actionable, and achievable health outcome goals within the context of their care preferences [53]. In the three-goal model, care preferences are integrated into the different

types of goals, but the bottom line is the same, namely shared goals between a patient and several clinicians and other health care providers could help to align treatments and care interventions. Because all clinicians focus on the same outcomes, coordination is easier and conflicting recommendations fewer [43]. CoC and explicit care for GS or priority setting by a specific professional were both associated with GS between patient and professional and can be seen as facilitating factors for GS between clinician and patient. In addition, we hypothesise in line with Tinetti et al. [43 53] that the integrated use of the same goals by all health care professionals who are involved in the care for a certain patient, could contribute to interprofessional CoC. Next to an efficient underlying ICT infrastructure, and a solution to privacy and safety issues, it is of utmost importance to define roles and responsibilities in a system of interprofessional continuity of care, especially if a patient's roles are also shifting. It seems reasonable to assign one of the involved clinicians as coordinating clinician.

The macro level: Societal factors

What would be the principles of design of a health care system which would be supportive of a goal-orientation in care? At the societal level, the bio-ethical environment and the health care system overall are not suitable for a goal-orientation of care yet. For a transition towards a system which gives room to goal-oriented decision-making and health care to take place, an underlying alignment of health care structure, proper financial incentives [60] and supporting and safeguarding legislation are important. Furthermore, society will have to provide the prerequisites for health ICT to develop safely and efficiently. It has to be decided what principles of design, considering aspects like privacy, access, ownership, transparency, safety, security of a ICT supported health care system are expedient.

Methodological considerations

To examine the research objectives of this thesis, we used a variety of research methods. These were a systematic review, quantitative logistic regression modelling and two qualitative methods, namely framework analysis and thematic analysis. For all studies we used the relevant research and reporting guidelines as mentioned in the separate chapters of this thesis. Specific limitations of the various studies have already been discussed in this thesis' studies chapters. For our study we identified four topics of general methodological strengths and weakness:

- Early topic: developing concepts and terminology
- Different studies consider different types of goals
- Study participants and target population
- Qualitative research methods

Early topic: developing concepts and terminology

We concluded that this is an 'early' research topic due to developing concepts and terminology. This constitutes both a limitation in performing the research and a strength by providing a contribution to clarity in terminology and concepts.

As was discussed in the study specific discussions, we can state that terminology within our thesis topic is still developing. First of all, from our research and the literature it becomes clear that the content of the concept of SDM itself is in development. Not only in the context of the inclusion of GS as essential element, but also with regard to other aspects of the underlying concept and definition, as was described in chapter 5. One can, for example, wonder whether sharing of decision-making [14] is the same as SDM.

Considering GS, both CGS and shared goal setting and/or the sharing of treatment goals are used as terms. The collaborative character of the GS process is an important element of its contribution to a patient-centred orientation. In our research, we did not investigate the meaning and practicing of 'collaborative' in GS and 'shared' in SDM specifically. Careful interpretation of the collaborative character of GS is necessary. We chose to use the term CGS to align with Bodenheimer et al. [62]. Furthermore, in our view CGS refers to the process of GS without the limitation of a specific type of goal, like treatment goals. The term priority setting is also mentioned in relation to GS, as became clear in our systematic review. However, we propose to reserve that term for priority setting in goals, as element of the second phase of goal setting within the Team Talk.

Terminology used for the patient perspective is even more complex and sometimes confusing. Instead of goals, terms like wishes, expectations, priorities, health outcome goals, health priorities, preferences, preference construction, needs and values are used. As was also concluded by Knight et al.[63], the concepts of values, goals, and preferences are often used interchangeably, which builds the case for establishing consistent definitions within the context of health care decision-making as an important first step in enhancing PCC. In the paragraph *Goal-oriented shared decision-making: a next model for daily practice*, we elaborated further on terminology for the patient perspective.

For a patient goal-oriented approach in health care, also several terms are used in the literature, namely patient priority-directed decision-making and care, patient goals-directed care, patient goal-oriented health care and goal-oriented patient care. We chose to use patient goal-oriented health care and decision-making to reflect the relevance of goals and GS and the collaborative character of this approach. Maybe a next step would be for terminology to develop into *person* goal-oriented health care.

The above described discrepancies in concepts and terminology led to difficulties in identifying studies in the review, a solely focus of the quantitative analysis on determinants of sharing disease-and symptom-specific goals, possible problems in consistent use of concepts and terminology in the interviews and difficulties in relating findings to the

literature. However, by overcoming these limitations, our findings eventually made a significant contribution to conceptual clarity by means of the three-goal model and the proposed integration of the three-talk model and the three-goal model.

Different studies consider different types of goals

Our study contributes to further development of goal-oriented health care with older patients with one or more chronic conditions from two perspectives: clinical practice and theory development. Our topic can be seen as an 'early' topic, empirical evidence is just evolving, while theoretical views and insights are rapidly developing. As followed from our studies on goals and goal-orientation several types of goals exist. While we developed the three-goal model and introduced the new concept of fundamental goals, our research in chapters 2, 4 and 5 could not distinguish between these different types of goals, because this research considers regular clinical practice (chapter 2 and 4) or did not primarily distinguish between different types of goals (chapter 5). This is an important realisation in the interpretation of the results of these chapters.

Study participants and target population

Considering the target population, we primarily focused our research on older patients with a chronic disease or multimorbidity. In this sense we tried to focus on a target population with complex health care demands.

In the context of condition and functioning, ideally, we would have had specified this potential complexity of multimorbidity further by also including factors like disease severity and disability [42] and/or frailty [64]. However, these data were not consistently available and we consider this to be a limitation. Including these factors to increase the specificity of the target population could be a recommendation for further research.

There is strong association of multimorbidity with age and age is the main risk factor for the prevalence and incidence of multimorbidity [64]. Considering age, for the qualitative interviews, we asked the interviewees to use the context of care for people aged 75 or older. The selection criterion on age for studies to be included in the systematic review were a study population with a mean age ± standard deviation incl. age 65 and the study population of the CWF survey was aged 55 or older. For the systematic review this was due to feasibility reasons, there were hardly any studies specifically targeted at patients aged 65 or older. In the secondary analysis of the CWF data we used age as a variable to research whether it would be an important factor. Although we used different age criteria for 'older patients' for both research and pragmatic reasons, we do not consider this a major limitation, because our main goal was the provision of first insights in this complex topic. An important finding of our quantitative research was that age appeared to be less important as a potential determinant for sharing goals, in contrast to what we hypothesised beforehand.

Our qualitative studies and the systematic review used a health care professional perspective. The quantitative analysis was based on patient-reported data. Considering the health care professional, the consistent factor was 'caring for older patients with multimorbidity'. In the qualitative studies we specifically focused on GPs and CGs. In the systematic review and in the CWF analysis, the health care professional was not specified further. This could be considered a limitation. In addition, although the analysis on factors increasing the likelihood of sharing goals was based on patient-reported data, and the systematic review focused on interventions, the lack of the patient perspective in our qualitative studies is an important limitation to the findings and their interpretation. Further research on the patient perspective on goals, goal-orientation and SDM in relation to goals has high priority.

Qualitative research methods

Next to a systematic review and a logistic regression analysis we used qualitative research methods in this thesis. As also stated by Holloway and Todres [65], qualitative research methods are very diverse, complex and nuanced. We used both thematic analysis and framework analysis and consider this a strength of our thesis, because both approaches have their own goal. Framework analysis was used to compare our data with Makoul's framework, thereby the analysis departed from a theoretical position [66 67]. Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data independent of former theoretical frameworks [67]. Therefore, we considered this a useful approach for theory development on types of goals and goal-orientation in relation to SDM (chapter 3). A limitation in all qualitative research is that it provides knowledge on ideas, perceptions and ideas of participants, not their actual behaviour [68].

Implications and recommendations

A transformation from a disease-oriented approach to a patient goal-orientation in decision-making with older patients with multimorbidity will require further research and several changes in clinical practice and policy. In the following we will discuss implications and recommendations for research, clinical practice and policy.

Implications and recommendations for further research

This is an early and dynamic research topic. The results of this thesis offer many opportunities for further research. In the various chapters of the underlying research we already made recommendations. In addition, we suggest the following key areas for further research with a focus on CGS and G-SDM:

- Theory development
- Tools for clinical practice
- Implementation and evaluation

Theory development

Future combined theoretical and empirical research is needed to refine and validate the three-goal model. Evaluation and potential adaptation of the three-goal model on the basis of an analysis of patients' and caregivers' perspectives is a high priority area. Qualitative methods like, interviewing, expert consultation and international focus groups can be used for further refinement and validation of the model. Furthermore, larger surveys of patients and health care professionals could be performed and quantitatively analysed.

The integration of GS into a SDM approach with older patients with multimorbidity should also be topic for further research. In our view, further research on a model of SDM with older patients with multimorbidity, which would be an integration of our three-goal model into the recently updated three-model of SDM, and thus the development of a G-SDM approach, could be used as a starting point. Qualitative research methods, like interviewing of experts, patients and clinicians, and international focus groups could be used for that purpose. Specific attention to the collaborative character of CGS and G-SDM is necessary to associate with differences in competencies, wishes and context of patients, different contexts of the CGS and SDM process and different priorities between patients and clinicians. Furthermore, terminology should be made consistent. Our proposal on terminology based on the G-SDM model could be used as point of departure.

Following further research on a model and practical approach for CGS and G-SDM with a focus on patient and clinician, this research could be expanded to include an interprofessional perspective and usability. Following this line of thinking, we want to highlight the relevance of the aspect of effective collaborative action (ECA), which we defined as, clinicians and patient deciding on and performing diagnostic and treatment steps in line with collaborative goals.

Tools for clinical practice

Based on a validated three-goal model, we recommend developing, piloting and feasibility research on practical tools for GS of several types of interrelated goals. Especially tool development for fundamental GS is an important research area. The development of a practical tool consisting of concrete questions to operationalise the three-goal model would be recommended. Existing research on clarification of values, values' trade-off processes and advance care planning methods and experiences could be taken into account. Furthermore, it would be interesting, to determine how patient and clinician could achieve to set reasonable goals and how to take into account variations in context, competencies,

personality features, professional attitude and social context. An important question is what background, competencies and role in the care process would be conditional for health care providers to engage in GS with patients and how this could be influenced by education and training. Furthermore, the integration of these GS tools with interventions on SDM is a topic for research. Maybe new tools on G-SDM have to be developed, if integration in existing SDM tools is not feasible. For both an (interprofessional) three-goal model as for (interprofessional) G-SDM tools, it is clear, that these will have to be supported by health ICT solutions. These will have to be aligned with and connected to other data sources and tools (including digital health records of clinicians and of patients themselves) for optimal use. Furthermore, the relation with other multifactorial interventions should be researched further. Ideally, an instrument for CGS of several types of goals is applicable for integration in other complex interventions, including SDM. We recommend developing tools which are also valuable for interprofessional use, based on the hypothesis that collaborative goals could contribute to improved alignment and consistency of diagnostics and treatments when several health care professionals are involved.

Implementation and evaluation

For efficient implementation it is probably important to know, who will benefit most from this approach to start implementation with those individuals, in line with views on the implementation of care planning in general [54]. Further research should include methodological innovation for the evaluation of complex GS and G-SDM intervention studies. Barriers and facilitators for the implementation of CGS and the integration of goals into SDM is also a topic which needs attention.

In our reflection on main findings we discussed three levels of potentially influencing factors in the development and implementation of CGS and G-SDM. Considering the relation between patient and clinician and clinician's attitude, interesting research questions could be the following: For which patients under whom circumstances will goal-oriented health care be achievable? Is goal-oriented medicine achievable for all physicians? Can a goal-oriented approach be learned? Is it suitable for all medical specialties? Considering guideline development, we suggest research to focus on advanced multimorbidity research. This includes: the link with frailty [64], clustering of conditions [50], and the acquirement of patient outcome-based evidence to inform goal-based guidelines, thus translating patients' goals into care options [53]. Furthermore, the possibilities and consequences of individual diagnostic and treatment advice by artificial intelligent analysis, constituting personalisation of guidelines towards individual patients from a biomedical perspective, have to be examined. In addition, a meta-guideline on GS and goal-attainment could be developed, giving opportunities for further personalisation of care decisions based on individual goals. Quality metrics could be partially related to

GS and goal attainment. Furthermore, CoC, and more specifically interprofessional CGS and G-SDM are important topics for further research. Optimisation of the infrastructure and health ICT solutions and the necessary preconditions for its use are a key conditional factor for further development of a goal-orientation of care. In the macro-context, from our research it followed that country was a factor associated with the likelihood of sharing goals. It would be very interesting to further deepen this association and its potential underlying factors, since this could provide knowledge on factors relevant for successful implementation. Furthermore, a societal discussion is necessary as to which conditions are necessary and how these could be accomplished, considering elements like privacy, transparency, responsibilities, safety and security. This is complex because societal factors, especially in an international context are not easily tackled. Next to the potential influencing factors we just discussed, research is necessary to discover additional influencing factors at the micro-, meso- and macrolevel.

Implications and recommendations for clinical practice

Considering goals and GS in daily practice we concluded in chapter 4 and 5 that the sharing of goals is no regular care yet and the development and evaluation of practical tools is only just evolving. Following this finding, interpreting results and giving recommendations based on the three-goal model and a potential G-SDM approach, which are still in their conceptual phase, is far-reaching. This does not mean that the three-goal model has a primary conceptual focus. In fact, it aims to contribute to the development of practical tools for translating and operationalising rather abstract aspects like values, core relationships and personal history and circumstances in several types of usable goals for daily practice and integrating these into SDM processes. In the following, we try to show what implications could be for clinical practice, if this approach would be implemented.

In a well-known and often cited paper on CPGs and quality of care for older patients with multiple co morbid diseases by Boyd et al. [45], the problem of disease focused clinical guidelines to patients with several chronic diseases was already addressed. In this research it was examined how CPGs address co morbidity in older patients and explored what would happen when multiple single-disease CPGs would be applied to a hypothetical 79-year-old woman with 5 common chronic diseases. Patient-centred aspects of medical decision-making were partial focus of the analysis and included a discussion in the CPGs of quality of life, physical function, or symptoms such a pain and dyspnoea, differentiation between short-and long-term effects, goals of treatment, the incorporation of patient preferences or SDM, and the burden of following recommendations. It was concluded that the hypothetical treatment regimen would be fairly impossible to perform and at huge financial and personal costs. Furthermore, it was concluded that there was a lack of discussion of balancing short- and long-term goals, quality of life and guidance on the

incorporation of preferences. How could the application of the three-goal model and G-SDM be helpful here? Imagine the following:

A 79-year-old woman with 5 common chronic diseases visits her GP because of tiredness. She is married to a 80-year-old man with a developing dementia syndrome, who is very attached to and dependent on his house, garden and regular patterns. She has 3 children living at a distance and one child living in the same village. She has always been a practicing catholic; however, after the loss of a grandchild due to suicide, she has religious doubts. Her daughter in the same village always helped in taking care of her father, but she is having a depression and actually needs care herself. This woman knows that her husband would rather die than leaving his house and garden. She has always been caring for her husband and children, but her health is deteriorating. In fact, taking care of the house, garden, her husband and now also daughter and her family is becoming a burden. She has always been a strong, independent woman, but she cannot handle it anymore. Sometimes she dreams of having a small apartment in town, being at rest and waiting for death to come. For her as a person, she has had a fulfilled life. She is very tired lately. Her GP fears that there is also an underlying serious disease and recommends further diagnostics.

If this GP and this 79-year-old woman would engage in GS, they could start a discussion on fundamental goals, meaning a discussion on core relationships, important values and especially trade-offs between those values and other potential influencing aspects, like religious persuasion. Several values and core relationships are important to this woman and are in conflict. Her personal history of the loss of her grandchild also colours her considerations. Furthermore, the clinician also has recommendations and priorities. In a fundamental GS process values, core relationships and personal meaning of quality of life could be discussed, making conflicts transparent and deciding on fundamental goals. An outcome of this fundamental GS process could be that it is so important for her to keep on taking care for her husband that she takes the first step of engaging into a diagnostic trajectory, although for herself she would have peace not to know and take everything as it comes. The process of making this fundamental goal explicit is useful on its own, because this makes potential conflicts explicit and open for discussion. Furthermore, the understanding of the meaning of certain goals by both patient and clinician can be verified. The outcome, an explicit fundamental goal, is usable, not only for further GS of other types of goals but also for alignment with other health care providers. The GP discusses this fundamental goal of 'staying able to take care of her husband as long as possible' with the CG. A carcinoma of the stomach is diagnosed. Again, a GS process takes place, ideally between patient, GP and CG. The patient stays to her original fundamental goal. This is of utmost importance to her and more important than increasing her chances

of survival. For the treatment of the carcinoma, this means that she will take surgery, but no chemotherapeutic treatment. The GP, who knows this woman already for 25 years, would have decided differently if he would have been the decision-maker on his own, but he is at peace with the transparent considerations and the explicit discussion on this important decision. This is written in her care plan by the GP, which can also be used in the regional hospital. If this patient is visiting a orthopaedic surgeon because of increasing pain due to arthrosis of her right knee a few months later, again her treatment goals and options are weighed against her fundamental goals and related functional goals. The orthopaedic surgeon can see that earlier this woman valued her care taker role constituting quality of life for her more than prolonging life. In a discussion with this woman, her priority functional goal is described as 'staying mobile as long as possible'; and treatment options, like surgery, NSAID's and injection therapy, are aligned with functional and fundamental goals. This woman chooses NSAIDs and stomach protection, taking the risk of bleeding of her stomach above knee surgery and revalidation, which would mean that her husband would have to go to the nursing home again, which had deteriorated his condition very much the first time when she was having her surgery because of her carcinoma. A few weeks after her visit of the orthopaedic surgeon, her GP is on leave and a GP on call visits her in the evening. This GP knows right away this patient's goals and underlying considerations, is able to verify quickly and new decisions can be taken accordingly.

Four months later her husband dies. This is a major life event, which asks for a renewal of the fundamental goal setting process and potential reconsideration of other goals and treatment decisions. A month after his dead, her GP visits her and proposes to have a new discussion on her goals.

This hypothetical case shows difficulties and trade-offs in complex decision-making and the potential added value of CGS of different types of goals, including explicit fundamental goals, and incorporating these goals in the decision-making process. This helps to handle complexity and increases patient-centredness and CoC in decision-making. Considering potential barriers and facilitators, from our research it followed that a patient-centred attitude, in the sense of exchange of information and a professional asking questions and CoC are potentially important factors in making this approach successful. Education and post graduate training of skills and attitudes for GS for health care professionals could be an important facilitator. Further development of guidelines and quality metrics could use GS of different types of goals as a further improvement of quality of care and its measurement for complex patients. ICT solutions could be helpful in providing necessary support for these processes.

Implications and recommendations for health policy

An implementation of patient goal-oriented decision-making needs several prerequisites. Alternative approaches to organise care should be considered, with an orientation at patient priorities [53]. Especially if several health care professionals are involved. Legislation, financial incentives and health ICT infrastructure and solutions have to be adapted to support this transition. Legislation should account for the possibility of adaptation of quality and performance metrics of dependence on GS and goal attainment. Further development is necessary for health ICT to support the efficient provision of goal-oriented health care, for example tools to coordinate care and share care plans which were collaboratively developed by clinician and a patient [26 53]. Government should facilitate the conditions for a safe and patient-centred implementation of necessary health ICT solutions. This means consideration of relevant legislation considering privacy, professional codes and standards and patient-clinician contact and prerequisites for further development of health ICT standardisation. In pay-for-performance systems, instead of fee-for-service systems, further development of patient value-based health care should be considered to be used as a starting point, including non-face-to-face visits [43 69]. Society can be supportive of a patient-centred and goal-oriented approach, but is now facing the next step. A fundamental societal discussion is important about the bio-ethical environment of goal-oriented health care and the development of necessary prerequisites.

Conclusions

Our study contributes to further development of goal-oriented health care with older patients with one or more chronic conditions from two perspectives: clinical practice and theory development. Our topic can be seen as an 'early' topic, empirical evidence is just evolving, while theoretical views and insights are rapidly developing. We aimed to contribute to both empirical evidence as well as theory development, but linking our empirical and theoretical research was challenging especially due to existing inconsistencies in approaches and terminology and the tension between familiar and new goal concepts. Our recommendations for further research benefited from these challenges. Our main conclusions are the following:

1. Integrating an explicit and unequivocal goal setting component into an approach of SDM with older patients with multimorbidity is necessary to associate with daily practice, to reach unambiguous terminology and to further develop practical approaches for incorporating patient values, preferences and context.
2. Clinicians use several types of goals in their orientation of care. We developed the three-goal model consisting of disease-specific or symptom-specific goals, functional

goals and goals specifying a patient's priorities in life, such as their values and core relationships in a certain decision-making context, which we labelled fundamental goals. Explicit fundamental goals can serve as anchor points in decision-making.

3. We observed a relative lack on single interventions of CGS and / or priority setting in clinical practice. Multifactorial interventions, like Guided Care, HOPES, ISCOPE and the Collaborative Care Model, including explicit attention for CGS or priority setting by a professional, show statistically significant positive effects on the application of goal setting, the number of advance care plans or the inclusion of goals in care plans.
4. Country, continuity of care, especially a professional asking questions, and information exchange increase the likelihood of sharing goals between community dwelling older patients and health care professionals. Patient characteristics, like age, had less impact as expected beforehand.
5. For older patients with multimorbidity we hypothesised a goal-oriented shared decision-making model (G-SDM) which integrates a two-phase goal setting element, consisting of 1. goal setting of fundamental goals, functional goals and disease or symptom-specific goals (three-goal model) and 2. the prioritisation of goals, into the three-talk SDM model, thereby incorporating patient values, preferences and context into decision-making and providing consistent and unequivocal terminology.
6. The actual health care system is not entirely supportive of a goal-oriented approach in decision-making and health care yet. A societal discussion is important about the bio-ethical environment of goal-oriented health care and its prerequisites, including legislation, financial incentives and health ICT infrastructure and solutions.

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CHAPTER 7

Samenvatting

Patiënten met meerdere chronische aandoeningen, ook wel multimorbiditeit, hebben baat bij zorg die tegemoet komt aan hun vaak complexe behoeften. Hun behoeften zijn vaak complex omdat deze kunnen voortkomen uit verschillende, met elkaar in interactie zijnde aandoeningen. Daardoor komt idealiter meer nadruk te liggen op het optimaliseren van functioneren in plaats van het zo optimaal mogelijk behandelen van individuele aandoeningen en gaan levensvragen steeds meer een rol spelen. Een persoonsgerichte benadering is daarom essentieel.

Gezamenlijke besluitvorming is een proces van besluitvorming dat aansluit bij een persoonsgerichte benadering. In gezamenlijke besluitvorming delen artsen en patiënten het best beschikbare wetenschappelijk bewijs bij het nemen van besluiten over diagnostiek en behandeling, en worden patiënten ondersteund in het afwegen van de verschillende mogelijkheden, om zo samen met de desbetreffende arts te komen tot *geïnformeerde* voorkeuren. Gezamenlijke besluitvorming blijkt echter zeker nog geen routine en het huidige model voor gezamenlijke besluitvorming, wat in eerste instantie werd ontwikkeld in de curatieve zorg, lijkt ontoereikend te zijn in de zorg voor oudere patiënten met een complexe zorgvraag.

Waarom is het huidige model van gezamenlijke besluitvorming ontoereikend voor deze doelgroep? We identificeerden een aantal factoren die hier mogelijk aan bijdragen, namelijk: de primair ziektegerichte focus van de huidige zorg, de complexiteit van de zorgvraag als gevolg van multimorbiditeit en mogelijke problemen bij het integreren van de waarden en voorkeuren van patiënten in de keuzen en besluiten.

Om processen van besluitvorming beter te laten aansluiten bij behoeften van oudere patiënten met chronische multimorbiditeit, is een volgende stap nodig in de ontwikkeling naar een gepersonaliseerde, persoonsgerichte benadering. Zorg en besluitvorming zouden zich moeten ontwikkelen van een oriëntatie gericht naar de verschillende ziekten en aandoeningen, naar een oriëntatie gericht naar aan de besluitvorming gekoppelde en bij voorkeur in gezamenlijkheid bepaalde doelen. Bij een oriëntatie op doelen in besluitvorming kan de focus liggen op uitkomsten die individuele aandoeningen ontstijgen en er ontstaat mogelijkheid om individuele prioriteiten te stellen in de verschillende afwegingen. Het samenspel van doelen, prioriteiten en gezamenlijke besluitvorming zouden kernelementen kunnen vormen van een volgende stap in de ontwikkeling naar een persoonsgerichte benadering van patiënten met een complexe zorgvraag. Echter, in de context van oudere patiënten met chronische multimorbiditeit en een doelgeoriënteerde benadering van zorg en besluitvorming, werd het belang en de rol van doelen, het proces van doelbepaling en de relatie tussen doelen, prioriteiten en gezamenlijke besluitvorming nog niet eerder nader gespecificeerd.

Uitgaande van de meerwaarde van een transitie van een ziektegeoriënteerde naar een doelgeoriënteerde benadering van besluitvorming, identificeerden we drie uitdagingen, namelijk:

1. Doelbepaling tot onderdeel te maken van reguliere zorg
2. Het vergroten van inzicht in typen doelen en benaderingen van doelbepaling
3. Het verhelderen van de conceptuele relatie tussen doelbepaling en gezamenlijke besluitvorming.

Vanuit het perspectief van een ontwikkeling naar een oriëntatie op doelen van gezamenlijke besluitvorming met oudere patiënten met chronische multimorbiditeit, blijkt er sprake te zijn van een gebrek aan kennis over zowel typen doelen, als het incorporeren van expliciete doelen en doelbepaling in modellen van gezamenlijke besluitvorming als wel aan praktische toepassingen binnen deze benadering.
In deze studie werd onderzoek gedaan naar doelen en doelbepaling in relatie tot gezamenlijke besluitvorming in de context van doelgeoriënteerde zorg en besluitvorming. Het voornaamste doel van dit proefschrift was om een kennisbijdrage te leveren aan de transitie van een ziektespecifieke benadering van besluitvorming naar een doelgeoriënteerde benadering vanuit het perspectief van zowel de theorieontwikkeling als de klinische praktijk. Hierbij werden de volgende vier doelstellingen geformuleerd:

1. De analyse van het concept 'doelbepaling' in de context van gezamenlijke besluitvorming.
2. Het vergroten van inzicht in mogelijk verschillende typen doelen en de oriëntatie van besluitvorming op deze verschillende typen doelen.
3. Het bepalen van de beschikbaarheid en effectiviteit van interventies gericht op gezamenlijke doelbepaling.
4. Het identificeren van factoren die het bepalen van doelen in de dagelijkse praktijk beïnvloeden.

De volgende vier onderzoeksvragen werden geformuleerd:

1. Wat is de visie van artsen op het concept van doelbepaling in de context van gezamenlijke besluitvorming?
2. Wat is de visie van artsen op doeloriëntatie in de context van doelbepaling en gezamenlijke besluitvorming?
3. Wat zijn effectieve interventies die gezamenlijke doelbepaling of het stellen van prioriteiten in gezondheid ondersteunen?
4. Welke karakteristieken van patiënten, relatie- en communicatie aspecten tussen patiënt en zorgverlener en context factoren, hebben invloed op de waarschijnlijkheid dat zorgverleners doelen bespreken met oudere patiënten met chronische aandoeningen?

Dit proefschrift draagt bij aan verdere ontwikkeling naar een oriëntatie van zorg en besluitvorming voor oudere patiënten met een of meer chronische aandoeningen naar doelen vanuit twee perspectieven: klinische praktijk en theorieontwikkeling.

De eerste en tweede doelstelling richtten zich op theorieontwikkeling. **De eerste doelstelling** om het concept van doelbepaling in de context van gezamenlijke besluitvorming te analyseren werd geadresseerd in **hoofdstuk 2**. Op basis van framework analyse van 33 interviews met klinisch geriaters en huisartsen, werden visies op het concept van doelbepaling in de context van gezamenlijke besluitvorming onderzocht. Zestien van de geïnterviewde artsen zag doelbepaling als een geïntegreerd element van gezamenlijke besluitvorming. Zeventien artsen noemden doelbepaling niet als expliciet element van gezamenlijke besluitvorming. Uit onze analyse volgden twee potentiële redenen voor deze observatie, namelijk het gebruik van andere terminologie in plaats van doelen, zoals voorkeuren, en een visie op doelbepaling als zijnde een gescheiden maar gerelateerde benadering. Op basis van onze resultaten kunnen we concluderen dat een model van gezamenlijke besluitvorming zonder expliciet element van doelbepaling deficiënt is en een belangrijk element van het betrekken van patiënten in besluitvorming mist. Integratie van expliciete doelbepaling in het proces van gezamenlijke besluitvorming kan bijdragen aan het bepalen van consistente terminologie van begrippen als doelen, prioriteiten, voorkeuren en waarden, sluit aan bij de relevantie van expliciete doelbepaling voor het proces van gezamenlijke besluitvorming, en legt de basis voor de toekomstige ontwikkeling van praktische methoden voor doelbepaling in relatie tot gezamenlijke besluitvorming.

Hoofdstuk 3 richtte zich op **de tweede doelstelling** om een kennisbijdrage te leveren aan mogelijk verschillende typen doelen in besluitvorming en het inzicht in de oriëntatie op doelen te vergroten. Op basis van thematische analyse van 33 interviews van klinisch geriaters en huisartsen, ontwikkelden we een *drie-doelen* model, bestaande uit ziekte- of symptoomspecifieke doelen, functionele doelen en fundamentele doelen. We introduceerden het concept van 'fundamentele doelen', gedefinieerd als doelen die levensprioriteiten, zoals waarden en belangrijkste persoonlijke relaties, specificeren en concretiseren, en persoonlijke keuzen in weging en afruil van deze aspecten expliciet maken. Fundamentele doelen kunnen gebruikt worden als referentie punten voor besluitvorming. Binnen het *drie-doelen* model zijn doelen aan elkaar gerelateerd. Ziekte- of symptoomspecifieke doelen bouwen voort op functionele doelen en beide bouwen voort op fundamentele doelen. Dit *drie-doelen* model zou kunnen fungeren als leidraad voor doelbepaling in de klinische praktijk. Uit de analyse bleek, dat artsen verschilden in het betrekken van fundamentele doelen in de besluitvorming. We onderscheidden drie categorieën: artsen met een primaire focus op functionele en/of ziektespecifieke of symptoomspecifieke doelen; artsen die fundamentele doelen impliciet betrokken bij de besluitvorming en artsen die fundamentele doelen expliciet betrokken bij de

besluitvorming. Daarnaast bleek uit de analyse dat er verschillende redenen zijn, waarom de bepaling en het gebruik van fundamentele doelen toegevoegde waarde kan hebben, namelijk: verschillen tussen patiënt voorkeuren enerzijds en richtlijnen en voorkeuren van artsen anderzijds, het mogelijk verschillen van de voorkeuren van mensen in soortgelijke situaties, en als cruciale informatie in acute situaties.

De derde en de vierde doelstellingen richtten zich op de klinische praktijk. **De derde doelstelling** naar de beschikbaarheid en effectiviteit van interventies gericht op het bepalen van doelen en / of het stellen van prioriteiten, werd behandeld in **hoofdstuk 4** middels een systematisch literatuuronderzoek. Dit systematisch literatuuronderzoek beperkte zich tot een studie populatie van patiënten met ten minste 1 chronische aandoening. De leeftijd van 65 jaar moest vallen binnen de range van de gemiddelde populatieleeftijd ± de standaard deviatie. Er werd geen onderscheid gemaakt in zorgdomein. Gevonden interventies richtten zich op: 1. Gezondheids- en behandel prioriteiten (Preferences in treatment planning for older patients (PrefCheck) interventie), hoogste prioriteiten voor de optimalisatie van gezondheid en kwaliteit van leven (Guided Care interventie), zowel doelen als wilsverklaringen (Helping Older People Experience Succes (HOPES) interventie), gepersonaliseerde doelen (Collaborative Care Model (CCM) interventie) en prioriteiten en doelen (Integrated Systematic Care for Older PEople (ISCOPE) interventie). In geen van deze interventies werden doelen en prioriteiten nader gespecificeerd.

Wat betreft effectieve interventies om gezamenlijke doelbepaling te ondersteunen, concludeerden we dat dit een relevant maar 'vroeg' onderwerp voor onderzoek is. Het betrof voor het merendeel multifactoriële interventies. We vonden alleen interventies die plaatsvonden buiten een ziekenhuisomgeving. Veelbelovende interventie componenten waren: expliciete aandacht voor doelbepaling en het stellen van prioriteiten door een specifieke zorgverlener, betrokkenheid van mantelzorgers, het plannen van zorg en training en opleiding van zorgverlener en patiënt.

Hoofdstuk 5 behandelde **de vierde doelstelling** naar de bepaling van karakteristieken van patiënten, relatie- en communicatieaspecten tussen patiënt en zorgverlener en context factoren, die invloed hebben op de waarschijnlijkheid van het bespreken van doelen in de dagelijkse praktijk. Gegevens van de Commonwealth Fund 2014 survey werden hiervoor gebruikt. Deze survey werd gehouden onder thuiswonende mensen van 55 jaar en ouder, woonachtig in 11 verschillende landen. Het hebben van ten minste een chronische aandoening was een voorwaarde voor respondenten om de survey-vraag te beantwoorden welke we hebben gebruikt als basis voor de uitkomstvariabele. Er werd geen onderscheid gemaakt in zorgdomein. In de analyse werden twee logistische regressiemodellen gebouwd: *model 1* voor de hele populatie en *model 2* voor respondenten met continuïteit van zorg. Land, continuïteit van zorg, informatie-uitwisseling over stress en leefstijl en een zorgverlener die vragen stelt (in het geval van continuïteit van zorg) hadden de grootste

invloed op de waarschijnlijkheid dat doelen werden gedeeld. Patiënt karakteristieken, zoals leeftijd, hadden minder invloed dan verwacht.

Hoofdstuk 6 startte met een korte beschouwing van de verschillende typen doelen die centraal stonden in de verschillende deelonderzoeken om de interpretatie van de resultaten te structureren. In het systematisch literatuuronderzoek (hoofdstuk 4) en de secundaire analyse van de CWF survey (hoofdstuk 5) was het nog niet mogelijk om onderscheid te maken tussen verschillende typen doelen. De framework analyse (hoofdstuk 2) maakte ook geen onderscheid tussen verschillende typen doelen. In hoofdstuk 3 stonden de verschillende typen doelen juist centraal.

Vervolgens gaf hoofdstuk 6 een Engelstalige samenvatting van de belangrijkste bevindingen van dit proefschrift, besprak het bijbehorende kader van persoonsgerichte zorg, evidence-based medicine en beroepsrichtlijnen in relatie tot ons onderzoek en introduceerde een mogelijk model voor doelgeoriënteerde gezamenlijke besluitvorming.

Dit model wordt gevormd door een integratie van het drie-doelen model en het 'Three-Talk' - gezamenlijk besluitvormingmodel bestaande uit de onderdelen 'Team Talk, Option Talk, Decision Talk', wat in 2017 werd herzien. Bij de herziening van het 'Three-Talk' model, is aan het onderdeel Team Talk het identificeren van doelen en het exploreren van overkoepelende doelen van patiënten in relatie tot gezondheidsproblemen toegevoegd. De nadruk op de relevantie van doelen en het includeren van doelen en doelbepaling in de Team Talk is een bevestiging van het onderzoek voor dit proefschrift. Daarnaast stellen we voor om in een geïntegreerd model de doelbepaling binnen de Team Talk te laten bestaan uit twee fasen. Doelbepaling van de verschillende typen doelen op de drie niveaus in de eerste fase en het prioriteren van de bepaalde doelen aan de hand van het voorliggende probleem en het te nemen besluit in de tweede fase. Dit proces van doelbepaling in twee fasen zou moeten leiden tot doelen, die relevant zijn voor het desbetreffende besluit en die de input vormen voor volgende stappen van het besluitvormingsproces. Uitkomsten van dit gezamenlijk besluitvormingsmodel zijn aan doelen gerelateerde besluiten.

Vervolgens besprak dit laatste hoofdstuk relevante factoren op micro-, meso- en macroniveau in de ontwikkeling naar doelgeoriënteerde gezamenlijke besluitvorming, beschreef het sterke en zwakke punten van de methodologie en gaf het een overzicht van de belangrijkste implicaties en aanbevelingen voor nader onderzoek, de dagelijkse praktijk en het beleid.

Concluderend kunnen we stellen dat deze studie heeft getracht een bijdrage te leveren aan de verdere ontwikkeling naar doelgeoriënteerde zorg voor oudere patiënten met multimorbiditeit, zowel vanuit het perspectief van theorieontwikkeling als vanuit het perspectief van de klinische praktijk. Dit onderwerp moet worden gezien als een 'vroeg' onderwerp omdat empirisch bewijs nog in de kinderschoenen staat, terwijl theoretische inzichten al verder in ontwikkeling zijn. Het verbinden van onze inzichten in theorieontwikkeling en

de klinische praktijk was complex door inconsistentie in benaderingen en terminologie en door de spanning tussen bekende en nog onbekende doelconcepten. We trekken de volgende conclusies:

1. De integratie van een eenduidige en expliciete doelbepaling in het proces van gezamenlijke besluitvorming met ouderen met chronische multimorbiditeit is noodzakelijk voor de aansluiting bij complexe zorgvragen, voor het bereiken van eenduidige terminologie en voor de verdere ontwikkeling van een praktische benadering voor de incorporatie van waarden, voorkeuren en context van patiënten.
2. Artsen gebruiken verschillende typen doelen in hun oriëntatie van zorg. We ontwikkelden het drie-doelen model, bestaande uit ziektespecifieke of symptoomspecifieke, functionele en fundamentele doelen. Fundamentele doelen zijn doelen die prioriteiten in het leven van een persoon, zoals waarden en belangrijke relaties, specificeren naar een bepaalde context. Concrete fundamentele doelen kunnen worden gebruikt als ankerpunten in de besluitvorming.
3. Er is sprake van een gebrek aan enkelvoudige interventies gericht op gezamenlijke doelbepaling en / of prioriteitsbepaling voor de klinische praktijk. Multifactoriële interventies met specifieke aandacht voor deze onderdelen door een zorgverlener, laten statistisch significante effecten zien op het toepassen van doelbepaling, het aantal wilsverklaringen of de inclusie van doelen in zorgplannen.
4. Het land waarin men woont, continuïteit van zorg, vooral in het geval van een zorgverlener die vragen stelt, en informatie-uitwisseling zijn van invloed op de waarschijnlijkheid van het delen van doelen tussen thuiswonende oudere patiënten en zorgverleners. Patiëntkarakteristieken zoals leeftijd hadden minder effect dan verwacht.
5. Ons hypothetisch doelgeoriënteerd gezamenlijk besluitvormingsmodel integreert een twee-fasen doelgesprek, bestaande uit 1. doelbepaling van fundamentele, functionele en ziekte- of symptoomspecifieke doelen (drie-doelen model) en 2. prioritering van doelen, in een gezamenlijk besluitvormingsproces. Dit geïntegreerde model incorporeert waarden, voorkeuren en context van patiënten in besluitvorming en voorziet in consistente en eenduidige terminologie.
6. Het huidige gezondheidszorgsysteem is nog ontoereikend voor een doelgeoriënteerde benadering van besluitvorming en gezondheidszorg. Een maatschappelijke discussie is nodig over de noodzakelijke randvoorwaarden in wetgeving, financiering / bekostiging en ICT om de ontwikkeling naar een doelgeoriënteerde benadering in de gezondheidszorg te bevorderen.

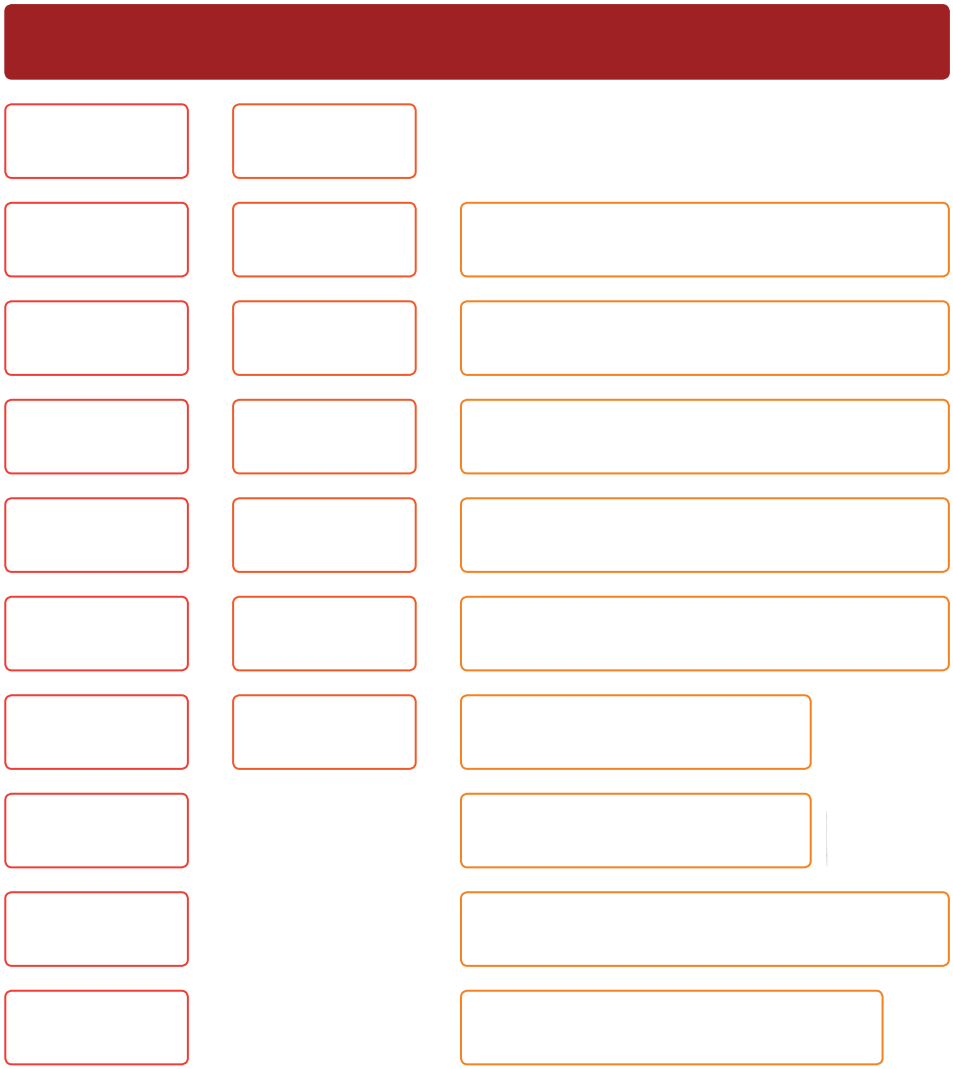
Words can paint,
but images have their
own language

Neeltje Vermunt

GOAL ...

7

... Thank you



Portfolio [3]

Scientific publications

- Vermunt NP, Harmsen M, Westert GP, et al., Collaborative goal setting with elderly patients with chronic disease or multimorbidity: a systematic review. *BMC Geriatr* 2017;(17):167.
- Vermunt NP, Harmsen M, Elwyn G, et al., A three-goal model for patients with multimorbidity: A qualitative approach. *Health Expect* 2017;1-11.
- Vermunt NP, Westert GP, Olde Rikkert MG, et al. Assessment of goals and priorities in patients with a chronic condition: a secondary quantitative analysis of determinants across 11 countries. *Scand J Prim Health Care* 2018; Jan 18:1-9.
- Vermunt NP, Elwyn G, Westert GP, et al. Goal setting is insufficiently recognized as essential part of shared decision-making in complex care for older patients: a framework analysis. *Submitted*

Oral scientific presentation

- *A three goal model for older patients with multimorbitiy*. At the 9th International Shared Decision-Making conference, 4 July 2017, Lyon, France.

Other publications

- Vermunt NP, Hooghiemstra TF, Naar een persoonlijk gezondheidsdossier dat werkt. *Lucide* 2015;(2): 59-63.
- Vermunt NP, Schols J, Verhey F. Besluitvorming bij dementie. Advance care planning met vertegenwoordigers. *Tijdschrift voor ouderengeneeskunde* 2013; 38(5):243-247.
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- Vermunt NP, Scheltinga MR, Roumen RM, et al. 'Tumor-to-tumor metastasis' van een cecaal adenocarcinoom naar een Grawitz tumor. *Medisch Journaal* 2002; 31(4):179-181.

Courses

- Zicht op ziekenhuizen, 2-days course, 2015, SBO
- Zorg en Verzekeringen, 14-days course, 2013-2014, Zorgverzekeraars Nederland
- Systematic Reviews, 3-hours course, 2013, IQ healthcare
- De Nederlandse Zorgmarkt, 4-days course, 2012, Zorgmarktadvies
- Qualitative Research Methods in Healthcare, 2-days course, 2012, IQ healthcare
- Introductie ATLAS.ti 7, 2-days course, 2012, Evers Research & Training

[3] This overview has a primary focus on the PhD trajectory. Council activities are not included.